

Duquesne University Duquesne Scholarship Collection

Electronic Theses and Dissertations

Summer 2013

Living with Dying in the Pediatric ICU: A Nursing Perspective

Debra Stayer

Follow this and additional works at: <https://dsc.duq.edu/etd>

Recommended Citation

Stayer, D. (2013). Living with Dying in the Pediatric ICU: A Nursing Perspective (Doctoral dissertation, Duquesne University). Retrieved from <https://dsc.duq.edu/etd/1235>

This Immediate Access is brought to you for free and open access by Duquesne Scholarship Collection. It has been accepted for inclusion in Electronic Theses and Dissertations by an authorized administrator of Duquesne Scholarship Collection. For more information, please contact phillips@duq.edu.

LIVING WITH DYING IN THE PEDIATRIC ICU:
A NURSING PERSPECTIVE

A Dissertation

Submitted to the School of Nursing

Duquesne University

In partial fulfillment of the requirements for
the degree of Doctor of Philosophy

By

Debra L. Stayer

August 2013

Copyright by
Debra L. Stayer

2013

LIVING WITH DYING IN THE PEDIATRIC ICU:
A NURSING PERSPECTIVE

By

Debra L. Stayer

Approved July 8, 2013

Dr. Joan Such Lockhart
Professor & Associate Dean Academic
Affairs, Duquesne University School of
Nursing
(Committee Chair)

Dr. Rick Zoucha
Associate Professor of Nursing, Duquesne
University School of Nursing
(Committee Member)

Dr. Betty R. Ferrell
Professor & Research Scientist
City of Hope National Medical Center
Duarte, CA
(Committee Member)

Dr. Mary Ellen Glasgow
Dean and Professor,
School Nursing

ABSTRACT

LIVING WITH DYING IN THE PEDIATRIC ICU: A NURSING PERSPECTIVE

By

Debra L. Stayer

August 2013

Dissertation supervised by Dr. Joan Such Lockhart, PhD, RN, CORLN, AOCN®, CNE, ANEF, FAAN

Caring for critically ill children who die quickly or whose condition progressively worsens is often overwhelming with the journey to the end justly stressful and difficult for all involved. Unequivocally pediatric ICU nurses spend a significant amount of time at the bedside attempting to meet and manage the palliative care needs of the children and their families during this arduous time. However, the literature lacks the perspective of the pediatric ICU nurse who provides palliative care to children with a life-threatening or life-limiting illness and their families. Therefore, a hermeneutic phenomenological inquiry to explore the essence of the experience provided by pediatric ICU nurses to children with life-threatening or life-limiting illnesses and their families was conducted. Semi-structured interviews were conducted with 12 pediatric ICU nurses who had

experience caring for dying children and their families in a rural tertiary level, non-freestanding children's hospital in northeastern United States. Data were analyzed using a descriptive and interpretive phenomenological approach. Participants' descriptions revealed the following five major themes: journey to death, a lifelong burden, challenges delivering care, maintaining self, and crossing boundaries. Findings from the study revealed the intricacies involved in caring for dying children and their families can be demanding at times; however, the study's participants voiced a great deal of professional satisfaction in caring for these children and their families.

Especially significant were the rich descriptions of the nurses' stories regarding the death of the child, the after death period and the memories of children who had died. Future research is suggested to explore spirituality and nurses' experiences of caring for children with life-threatening and life-limiting illnesses and their families as this was not evident in the study's findings. Additional research to discover pediatric ICU nurses experiences in urban settings with a more diverse sample of participants, with and without a pediatric advanced care team (PACT) could further expand this study's findings.

DEDICATION

I dedicate this dissertation to my family who has been influential and supportive in countless ways as I have pursued this professional dream. To my husband, Glenn, thank you for your constant encouragement and understanding. You are my best friend! To my daughters Kayla, Kelsey, and Kristy thank you for your patience and inspiration to keep going when the going got tough. May all your dreams come true too! I love you all!

ACKNOWLEDGEMENT

A very heartfelt thank you to my dissertation committee for their guidance and patience in helping me achieve this professional milestone.

To Dr. Joan Lockhart, my chairperson. Thank you for taking me under your wing, for giving me needed direction, for your kindness, and for sharing your wisdom with me.

To Dr. Rick Zoucha, my internal member. Thank you for going above and beyond and helping me get back up when I stumbled. Your thoughtfulness and patience are truly appreciated.

To Dr. Betty Ferrell, my external member. Thank you for answering my email! I am truly grateful to have had the privilege of your company. Thank you for sharing your expert knowledge of palliative care and for your kindness during this journey.

To my family, without you I am no one, you are the best!

To the pediatric ICU nurses for opening their hearts and sharing their stories.

To my dear friend and colleague, Dr. Lori Lauver. Thank you for your support and standing beside me every step of this journey!

To PhD cohort 16, you are simply the best! Thank you for being there when times were a bit rough.

TABLE OF CONTENTS

	Page
Abstract.....	iv
Dedication.....	vi
Acknowledgement.....	vii
Chapter 1.....	1
1.1 Introduction	1
1.2 Background.....	4
1.3 Significance.....	8
1.4 Purpose.....	9
1.5 Research Question.....	10
1.6 Definition of Terms.....	11
1.7 Assumptions.....	11
1.8 Limitations.....	12
1.9 Summary.....	12
Chapter 2: Review of the Literature.....	14
2.1 Introduction.....	14
2.2 Nursing Perspectives on Palliative Care.....	15
2.3 Death Attitudes.....	26
2.4 Factors Influencing Provision of Palliative Care and Pediatric Critical Care Nursing.....	31
2.5 Summary.....	36
Chapter 3: Methodology.....	38

3.1 Purpose.....	38
3.2 Methodological Framework.....	38
3.3 Research Method.....	47
3.4 Research Setting.....	47
3.5 Procedure for Protection of Human Subjects.....	48
3.6 Sample for the Study.....	50
3.7 Recruitment of Participants.....	51
3.8 Data Collection Instruments.....	52
3.9 Procedure for Data Collection.....	53
3.10 Procedure for Data Analysis.....	57
3.11 Establishing Rigor or Trustworthiness.....	60
3.12 Personal Aspects of the Researcher.....	62
3.13 Summary.....	65
Chapter 4: Findings.....	66
4.1 Introduction.....	66
4.2 Study Participants.....	66
4.3 Study Findings.....	69
Theme 1: Journey to death.....	70
Theme 2: A lifelong burden.....	89
Theme 3: Challenges delivering care.....	92
Theme 4: Maintaining self.....	106
Theme 5: Crossing boundaries.....	108
4.4 Summary.....	111

Chapter 5: Discussion.....	112
5.1 Introduction.....	112
5.2 Discussion and Interpretation of Findings.....	113
Theme 1: Journey to death.....	113
Theme 2: A lifelong burden.....	116
Theme 3: Challenges delivering care.....	116
Theme 4: Maintaining self.....	118
Theme 5: Crossing boundaries.....	119
Summary.....	120
5.3 Limitations of the Study.....	120
5.4 Implications and Recommendations.....	121
Nursing Practice.....	121
Nursing Education.....	121
Nursing Policy.....	122
Nursing Research.....	123
5.5 Summary.....	124
References.....	126
Appendix A.....	139
Appendix B.....	141
Appendix C.....	144
Appendix D.....	147
Appendix E.....	148
Appendix F.....	149

CHAPTER ONE

1.1 Introduction

The death of a child is a devastating experience. Although there have been significant advances in medicine, there are still children who will experience life-threatening or life-limiting conditions in which some will survive but some will die. Congenital heart defects, respiratory conditions, complications of prematurity, cystic fibrosis, Duchenne's muscular dystrophy, cancer, intractable seizures, human immunodeficiency virus (HIV), sudden infant death syndrome, intentional and unintentional injuries are a few examples of life-threatening and life-limiting illnesses children may encounter. The journey to the end, whether cure or death, is often challenging for all involved. Children who are facing these life-threatening or life-limiting illnesses and their families should have access to competent, compassionate, and developmentally appropriate palliative care offered at time of diagnosis (American Academy of Pediatrics [AAP], 2000).

Palliative care as defined by the National Consensus Project (NCP), (2013) states: Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice. The patient and family hopes for peace and dignity are supported throughout the course of the illness, during the dying process, and after death (p.9).

Moreover, it is important to remember children cannot be treated as small adults. Children have developmental differences, resiliency differences as well as diagnosis differences that present unique challenges to healthcare providers. All of these variances could possibly lead to a delay in the provision of palliative care (NHPCO, 2009). Pediatric palliative care has developed in response to continued demands for improvements in the care and support of children and families facing life-threatening and life-limiting illnesses (Knapp, 2009). Pediatric palliative care promotes a philosophy of care that focuses on identifying and providing physical, psychosocial, emotional, spiritual, and developmentally appropriate comfort through the use of an interdisciplinary team to a child with a life-limiting illness (Knapp & Contro, 2009). Additionally, children with decision-making ability should have the opportunity to provide assent to treatment, as well as voice their opinions regarding medical care (Kon, 2006; NCP, 2013). The goal of pediatric palliative care (PPC) is:

To best intersect with the aims of curing and healing, and this approach should be instituted at time of diagnosis for improving the quality of life, maintaining dignity, and ameliorating the suffering of the seriously ill or dying child in ways that are appropriate to their upbringing, culture, and community (Himmelstein, Hilden, Boldt, & Weissman, 2004, p. 1752).

Palliative care should begin at the time of diagnosis and continue concurrently with curative efforts regardless of outcome in all pediatric settings. The pediatric intensive care unit (PICU) is no exception. Unequivocally, providing pediatric palliative care in the PICU is essential, as nationally 80% of children who die in the hospital die in the PICU (Jones et al., 2007; Levetown, Hellsten, & Jones, 2010).

Pediatric ICU nursing while rewarding is equally challenging. One such potential challenge for the pediatric ICU nurse is caring for children who die due to life-threatening or life-limiting illnesses. Clearly it is the pediatric ICU nurse, perhaps more than any other health care professionals, who will spend significant amounts of time with these children and their families. It is often the pediatric ICU nurse who spends a considerable amount of time and energy attempting to identify, advocate for, and manage the palliative care needs of these children and their families. Often these children may be hospitalized for hours, days, weeks, months or years prior to death. Critically ill children facing a life-threatening or life-limiting illness and their families desire palliative care such as effective communication, comfort, mitigation of pain and other symptoms, alignment of care with the child and family's goals, and maximizing growth and development. Meeting these needs is essential to assist in attaining the best quality of life for children whether they are expected to benefit from intensive care unit (ICU) treatment or require end-of-life care and bereavement care (Knapp & Contro, 2009; Nelson et al., 2011). However, the challenges, complexities and perspectives health care professionals, specifically pediatric nurses, may experience when initiating and providing palliative care to children with life-threatening or life-limiting illnesses is limited in the literature (DeGraves & Aranda, 2005, Docherty, Miles, & Brandon, 2007).

During this difficult time, nurses may determine they are not prepared to provide palliative care or for assisting with the transition from curative care to end-of-life care. Hospice and palliative care nurses generally have received formal education regarding palliative care and death, and have support systems available to assist them in managing feelings regarding dying. Pediatric nurses typically have not received any formal

education regarding palliative care nor do they have support systems in place to assist with their feelings surrounding the death of children. Formal education affords the hospice and palliative care nurses with advanced knowledge, skills, and support to assist them in the multifaceted dying process (Barnard, Hollingum, & Hartfiel, 2006).

Consequently, pediatric nurses may be confronted with numerous physical, psychological, ethical, social, and spiritual dilemmas of their own to possibly create a challenge for them while handling the various situations which may arise during this difficult time for the child and family (Malloy, Ferrell, & Virani, 2006). Discovery of possible challenges these health care professionals may encounter when initiating and providing palliative care to children with a life-threatening or life-limiting illness could provide a greater understanding of the challenges. This enhanced understanding of challenges encountered could possibly lead to the development of effective models of caring for these children and families as well as the development of nursing practice implications (DeGraves & Aranda, 2005).

1.2 Background

The term palliative is derived from “palliate” which can be traced back to the medical dictionary of the late 14th century of the Elizabethan and Indo-European times (Morris, 1998). Palliate is defined as lessening the severity of (pain, disease) without curing or removing; alleviate; mitigate (*Free Dictionary online* (4th ed.). Palliative care is “a philosophy of care that evolved from the hospice philosophy to meet the gaps in care for seriously ill and dying patients” (Himmelstein et al., 2004, p. 1752). Historically the terms palliative care and hospice care were used interchangeably as no conceptual difference existed between them. However, during the 1990s palliative care became recognized as a specialty area and as a result, professional organizations, palliative care

programs, and scholarly publications developed. The World Health Organization (WHO) (1990) provided the first definition of palliative care that focused on comforting patients suffering from distressing symptoms of advanced cancer. However, the focus of this attention was primarily with the adult population with minimal consideration given to the pediatric population.

Although there have been significant advances in medical technology, thousands of children continue to die annually. Subsequently, pediatric palliative care has emerged over the last decade and continues to advance today as a field of interest with a focus of attaining the best possible quality of life for children facing a life-threatening or life-limiting illness. Numerous national initiatives and pediatric palliative care programs have evolved in response to a call to action by the Institute of Medicine (IOM) report *When children die: Improving palliative and end-of-life care for children and their families* (Field & Behrman, 2003). This IOM report identified that continued clinical research was necessary to identify the gaps in knowledge for improving palliative care, end-of-life care and bereavement care for this vulnerable and diverse population (Field & Behrman, 2003). Various definitions of pediatric palliative care are offered by professional organizations such as the American Academy of Pediatrics (American Academy of Pediatrics, Committee on Bioethics and Committee on Hospital Care, 2000), the IOM (Field & Behrman, 2003), the Association for Children's Palliative Care (ACT) (2008) and the National Hospice and Palliative Care Organization (NHPCO) (2009).

However, a fundamental principle that exists among these organizations is that pediatric palliative care should begin at time of diagnosis and continue throughout the illness trajectory, regardless of outcome and with the goal of improving the quality of life

being respectful of the child and family's needs, values and culture. The child and family are viewed as one unit. Any improvement in the child's quality of life, large or small, short-term or long-term could have an enormous positive impact not only for the child's immediate family but for the extended circle as well (Sumner, 2010).

Additionally, the literature has identified four significant attributes necessary for the approach to pediatric palliative care. The first attribute involves mitigating physical and psychosocial suffering associated with the disease process through effective management of all symptoms assessed frequently and comprehensively throughout the illness including end-of-life (Children's Project on Palliative/Hospice Services [ChiPPS], 2009; Friedrichsdorf & Kang, 2007; Kang et al., 2005; McSherry, Kehoe, Carroll, Kang, & Rourke, 2007; NHPCO, 2009). Dying children may be highly symptomatic. Some of these children could experience increasing and intractable suffering with these symptoms, often presenting a difficult and challenging time for patients and families (Drake, Frost, & Collins, 2003). Therefore, frequent assessments of the child may be necessary to evaluate the effectiveness of symptom management. Secondly, providing effective and developmentally appropriate open communication regularly with the child and family is essential concerning prognosis, planning, and treatment. "Parents of sick children value health care providers who communicate clearly, accurately, honestly, and empathically" (Kang et al., 2005, p.1030). Parents often prefer full disclosure of information regarding their child's condition to better grasp and make some sense of their current situation. (Meyer, Burns, Griffith, & Truog, 2002). Having an understanding of this information may allow the child and family to be better prepared regarding the decision-making process of treatment throughout the illness. The influence of family dynamics, cultural

and spiritual beliefs, previous experience with loss, and nature of the child's illness should be considered when speaking with families and adjusted accordingly. The third attribute is concerned with providing individualized and holistic palliative care at time of diagnosis along with curative treatment throughout trajectory of the illness and through bereavement. This care should assist to maximize growth and development to the extent the child is able, adding quality not simply quantity to life (Himmelstein et al., 2004; National Network for Pediatric Palliative Care, 2011; NPHCO, 2009). The fourth attribute, incorporates an interdisciplinary health care approach to treatment/therapies throughout the course of illness being respectful of the child and family's wishes. The interdisciplinary team should follow the child and family across settings through active treatment including end-of-life when necessary (ChiPPs, 2009; National Network for Pediatric Palliative Care, 2011; NPHCO, 2009; Thompson, Knapp, Madden, & Shenkman, 2009). Having an interdisciplinary health care approach could provide numerous perspectives as well as diverse expertise to achieve and provide quality patient/family-centered care through the good and bad of treatment (National Network for Pediatric Palliative Care, 2011; NPHCO, 2009). Moreover, pediatric palliative care strives to provide and preserve the integrity of the child and family by meeting the various needs encountered during the illness trajectory, providing anticipatory guidance and bereavement support as necessitated (NPHCO, 2009). Given the fundamental principle shared by the various pediatric organizations and the defining attributes identified in the literature, pediatric palliative care should be acknowledged and included as an essential component of care for every critically ill child facing a life-threatening or life-limiting illness (Nelson et al., 2011).

1.3 Significance

The death of a child is often inconceivable to comprehend. During this difficult time, it is important that pediatric ICU nurses possess the disposition necessary to deal with high levels of stress often surrounding the care provided for children with a life-threatening or life-limiting illness. However, this is generally acquired only after many years of clinical experience (Foglia, Grassley, & Zeigler, 2010). Whether one is experiencing their first loss or one of many losses, each loss is unique often leaving an indelible impression behind (Bowden, 2005).

Pediatric ICU nurses are an often forgotten group of critical care nurses faced with incomparable challenges in their work environment as they provide care to children and families (Foglia et al., 2010). The pediatric intensive care unit can be a demanding environment even for the seasoned nurse. These nurses are in a unique situation to assess and meet the needs of children and families who may be experiencing a life-threatening or life-limiting illness due to the significant amount of time spent caring for these children (Malloy et al., 2006). However, many pediatric ICU nurses may feel uncomfortable and inadequately prepared to care for children with life-threatening or life-limiting illnesses which may result in death (Waas, 2004).

A scant amount of research, some antiquated, regarding pediatric ICU nurses' experience of providing palliative care to children with a life-threatening or life-limiting illness and their families exists within the literature with the majority of this literature focused on childhood cancer (Davies et al., 1996; DeGraves & Aranda, 2005; Docherty et al., 2007; Hall, 1996; Olsen et al., 1998). Therefore, discovery of the PICU nurse's experiences may contribute insight for the development of nursing strategies for personal and professional stability which could facilitate providing safe, quality patient care for

the children (and families) during this challenging time. Moreover, knowledge gained from the experiences of the pediatric ICU nurses caring for these patients could provide information regarding factors that may impact their ability to provide palliative care. A greater understanding of the experiences could place pediatric ICU nurses in a significant position to improve the quality of patient care for the child (and family) during this arduous time. The development of direct nursing care strategies to achieve and heighten pediatric palliative care goals could minimize child (and family) suffering from a life-threatening or life-limiting illness thus possibly enhancing their quality of life (Foster, LaFond, Reggio, & Hinds, 2010). Thus, research obtained in pediatric palliative care may lead to implications for nursing practice which may reduce potential health care professional suffering when providing palliative nursing care and promote a healthy work environment, increased job satisfaction and retention of PICU staff (Alspach, 2007; Ernst, Franco, Messmer, & Gonzalez, 2004; Kotzer, Koepping, & LeDuc, 2006).

1.4 Purpose

The purpose of this hermeneutic phenomenological study is to explore the experiences of pediatric ICU nurses who provide palliative care to children with life-threatening or life-limiting illnesses and their families and to obtain an increased understanding of the meaning and interpretation of their experience. Accordingly, exploring the experience of providing palliative care through the perspective of the pediatric ICU nurse may reveal the essence of the phenomenon as well as an in-depth understanding of the contextual factors associated with the experience.

1.5 Research Question(s)

With the intent to advance the pediatric palliative care literature, the following research question is posed:

What is the essence of the pediatric ICU nurse's experiences in delivering palliative care to children with life-threatening or life-limiting illnesses and their families?

1.6 Definition of Terms

For this study, the following definitions of terms will be used.

Curative treatment approach. This approach encompasses treatment aimed at identifying and remedying the patient's medical issue (Coyle, 2010).

End-of-life care approach. This approach is typically reserved for the final weeks of life when death is imminent (Ferrell & Coyle, 2002). This approach assists individuals with advanced, progressive incurable illnesses to live as well as possible until they die. The focus of this approach is on preparing for an anticipated death, including management of pain and other symptoms and provision of psychological, social, spiritual support and support for the family into bereavement (Association of Children's Palliative Care [ACT], 2009).

Life-limiting illness/conditions. Those conditions for which there is no reasonable hope for cure and from which the child will die. However, there may be long periods of intensive treatment aimed at prolonging life, yet allowing normal activities and maintaining a quality of life (Association of Children's Palliative Care [ACT], 2009; NHPCO, 2009).

Pediatric nurse. A nurse who is intimately involved with the care of the child, from infancy through adolescence as well as the family in the various pediatric inpatient and outpatient clinical settings (Hockenberry & Wilson, 2010).

Pediatric palliative care approach. This approach should begin at time of diagnosis and continue regardless of the disease process outcome. It is often delivered in the context of prognostic uncertainty. It is the active total care of the child's body, mind, and spirit which is developmentally appropriate and in accordance with the family's values and cultural beliefs. Family support is also provided. The use of an interdisciplinary team to meet and alleviate the physical, psychosocial, spiritual, and developmental needs is essential (Wolfe, Hinds, & Sourkes, 2011).

1.7 Assumptions

This study will utilize a hermeneutic phenomenological approach to inquiry as the focus of the study is to interpret the essence of the experiences provided by the pediatric ICU nurses to children with life-threatening or life-limiting illnesses and their families.

The following assumptions which underlie this study of inquiry include:

1. The pediatric ICU nurses will provide genuine responses reflective of their thoughts and approaches regarding the experience of providing palliative care to a child with a life-threatening or life-limiting illness and their families.

2. Differing levels of tacit knowledge exist within this group of pediatric ICU nurses.

3. Palliative care should begin at diagnosis.

4. The pediatric ICU nurses desire the personal qualities and clinical expertise to support the child and their family through this difficult health experience.

5. The pediatric ICU nurses desire to advocate and provide for quality of

life for this vulnerable population.

1.8 Limitations

The following anticipated limitation is offered:

1. The ability of the participants to articulate and communicate their actual experiences rather than what they consider the researcher wants to hear.

1.9 Summary

The death of a child is devastating, “to cut short a life just begun is a raging injustice!” (Gettner, 2010, p. 239). Whether death is expected or not expected, it is often a difficult situation for health care professionals to handle, but it must be addressed. The pediatric ICU nurses typically spend a considerable amount of time and energy attempting to identify, meet, and manage the needs of these children and their families during this difficult time. However, these nurses typically have not received any formal education regarding palliative care nor have support systems in place to assist with their feelings about the multifaceted dying process. There is a paucity of research which relates to the nursing experiences of providing palliative care to dying children, specifically in the pediatric ICU. Research is needed to explore these experiences.

With discovery and subsequent understanding of the intricate experiences of providing palliative care to a child with a life-threatening or life-limiting illness that dies, pediatric ICU nurses may have the ability to positively influence the well-being of the child, thus improving their quality of life. Moreover, the identification of potential practice implications from the experiences shared could further guide the development of professional and personal boundaries for the pediatric ICU nurse also leading to

improved quality of care for the child with a life-threatening or life-limiting illness as well as job satisfaction and subsequent job retention.

CHAPTER TWO

REVIEW OF THE LITERATURE

2.1 Introduction

Clarke and Quin (2007) noted that providing palliative care to children and families is multifaceted and includes circumstances of uncertainty regarding the life-death trajectory. Accordingly, the reality remains that parents and healthcare providers often will choose and continue aggressive treatment to the very end of the child's life (Sumner, 2010). Many deaths which are encountered in the pediatric ICU may include transforming from aggressive curative care to end-of-life care with subsequent involvement of withholding or withdrawing of life supporting therapies. This transition may be difficult for the pediatric ICU nurse as it may become difficult to facilitate a consensus with the family regarding the child's prognosis, as hopefulness for a cure is no longer possible (Espinosa, Young, & Walsh, 2008).

Therefore, pediatric ICU nurses may be challenged by numerous quandaries of their own particularly when the focus of caring for a child with a life-threatening or life-limiting illness changes from cure to death. Pediatric ICU nurses may not feel adequately prepared to address and meet the needs of the child and family during this challenging time. Moreover, caring for critically ill children on a regular basis and the tendency to offer life-prolonging treatments could stimulate emotions of helplessness, anger, sadness, and unbearable stress in pediatric ICU nurses possibly impeding the quality of care they provide (DeGraves & Aranda, 2005; Foglia et al., 2010; Morgan, 2009).

This chapter will present a general discussion and overview of related literature focusing on pediatric palliative care, death attitudes and education, nursing perspectives

of pediatric palliative care, job satisfaction and job stress of pediatric ICU nurses; all are important concepts related to the approach of pediatric palliative care.

The electronic databases of PubMed, Ovid, CINAHL, MEDLINE, and PsychInfo from the years 1990 – 2012 were searched for English articles. Electronic search terms included: *nurse, nursing, death, death attitudes, death education, perspectives, pediatrics, palliative care, and pediatric palliative care, pediatric ICU, job satisfaction, retention and healthy work environment*. These terms were searched in multiple combinations to obtain published articles. The electronic search was limited to articles of English language studies with an abstract or full text. Furthermore, reference lists of retrieved articles were reviewed (ancestry approach) to identify additional relevant studies. A systematic review of the articles was conducted and inclusion criteria were based on whether the article was able to provide significant information relating to the topics of inquiry.

2.2 Nursing Perspectives on Palliative Care

Pediatric palliative care continues to emerge as a field of interest with a focus of attaining the best possible quality of life for children facing a life-threatening or life-limiting illness. This is a field of interest which is very different from adult palliative care and hospice that requires specialized knowledge, training and sensitivity of those healthcare providers to meet the unique needs of the child and family during a challenging time (Sumner, 2010). Caring for a dying child is multifaceted, both personally and professionally, for the pediatric ICU nurse. However, few experts have researched the experiences of pediatric ICU nurses providing palliative care (DeGraves & Aranda, 2005).

Two phenomenological studies (Barnard et al., 2006; Yang & Mcilfattrick, 2001) explored nurses' experiences of providing palliative care nursing in a hospital setting, specifically an adult palliative care unit and the adult intensive care unit. Barnard et al. (2006) explored the experience of being a palliative care nurse on an adult palliative care unit in a regional Australian hospital. A purposive sample of 15 nurses described their experience of being a palliative care nurse through semi-structured interviews. The research findings revealed five themes which described their understanding the experience of being a palliative care nurse and included: "(1) doing everything you can, (2) developing closeness with your patient and family, (3) working as a team, (4) creating meaning about life, and (5) maintaining myself" (Barnard et al., 2006, p.8).

The first three themes of the study relate to the journeying of the nurse with the patient through the disease trajectory. The ability to enhance the patient's quality of life through the development of close and personal relationships to truly understand patients and their needs, as well as the importance of a multidisciplinary team to meet the various needs of the patient and family were identified as necessary for this journey. The remaining two themes were specific to the personal life of the palliative care nurse. Recognition of the challenges related to palliative care nursing and the need for collegial support are essential to provide balance to the personal and professional lives of these nurses. The findings of this study revealed the complexity and challenges often faced by nurses providing palliative care (Barnard et al., 2006).

Yang and Mcilfattrick (2001) explored the experiences of caring for dying patients in the adult intensive care unit. A purposive sample of 10 nurses in two teaching hospitals in Taiwan participated in this study. Using a semi-structured interview process, data

analysis identified 13 main themes which were categorized into three main groups. These groups were: nurses' attitudes (fear and guilt, frustration and powerlessness, understanding, compassion and empathy, grief reaction, and an opportunity for growth when caring for these individuals); stressors (physician and nurse relationship, family's emotional response, concealing illness or prognosis from patient and do not resuscitate orders); coping strategies (providing good nursing care and influence of religious beliefs to assist in managing stressful situations and allowing for effective functioning in the ICU). The feelings of fear and guilt were coupled with the sense of powerlessness and frustration as the likelihood of a positive outcome for the patient was not probable and the goal for critical care nurses was cure not death (Yang & Mcilfattrick, 2001).

Additionally, in eastern cultures such as Taiwan, concealing an illness or prognosis from patients is a common practice. According to the participants of this study, not being able to inform the patients of their illness or prognosis created a great deal of moral tension as the nurses were uncomfortable with the inability to reveal this information to their patients who were facing death. The issue of explaining or reviewing with families the concept of 'Do Not Resuscitate' further compounded the nurses' degree of moral tension as in this study the responsibility of explaining a 'Do Not Resuscitate' order was often regarded by the participants as their responsibility (Yang & Mcilfattrick, 2001). The findings of this study have illuminated several difficulties and dilemmas experienced by intensive care nurses and uncovered some of the mystery regarding the circumstances which may arise when caring for adult patients dying in the ICU. Due to the diverse demands of caring for dying adults, incorporating principles of palliative care

specific to the adult ICU may assist nurses in the management of the numerous ethical and moral dilemmas which may possibly arise.

Georges, Gryndonck, and Deirckx De Casterle (2002) research was conducted to elicit and explore the way nurses working on a palliative care unit recognized their role as well as to gain insight and an understanding of the issues that arose on the unit. Using a constant comparative grounded theory method for analysis and participant observation and semi-structured interviews of 14 nurses for data collection, two main perceptions were reported from this study. These perceptions included: (1) striving to adopt a well-organized and purposeful approach as a palliative care nurse on an academic ward and (2) striving to enhance the well-being of patients.

While most nurses in this study acknowledged that a caring attitude was essential to enhance the well-being of patients, this attitude was often difficult to obtain due to the absence of a true hospice approach in the academic setting. The nurses voiced concern that a technical approach of care on this unit dominated over the holistic approach of care often associated with hospice care. The nurses expressed discontent as they felt this scientific approach did not support and enhance the development of palliative care nursing. The findings of these studies are suggestive of the difficulties in promoting and applying principles of palliative care in the hospital setting (Georges et al., 2002).

Clarke and Quin (2007) presented findings of professional carers' experiences of pediatric palliative care in Ireland in various settings such as hospitals, communities, individual families, and volunteer organizations. This study utilized a mixed-methods approach. However, for purposes of their article, only the qualitative data generated were offered. A purposive sample of 15 health care professionals was obtained. Participants

included: nurses, physicians, social workers, chaplains, and occupational therapists who provided unique insights into their understanding of the struggles and vulnerabilities of families and themselves as they strive toward providing palliative care for children with a life-limiting illness. Three themes were extracted from the open-ended questions provided to the participants. The themes included the clarity of definition and complexity of engagement, seeking to deliver a palliative care service, and emotional cost of providing palliative care. The participants' responses yielded a unique understanding of the struggles and vulnerabilities they faced in providing palliative care to dying children.

These responses included “attempting to provide palliative care without proper resources or services, emotionally challenging and difficulty offering support as staff struggle to provide quality continuous care, and attachment to the child and family” (Clark & Quin, 2007, p. 1228). The findings were suggestive of a repetitive experience of vulnerability which is consistent with the multiple and complex challenges encountered by health care professionals when providing palliative care to children with a life-limiting illness (Clarke & Quin, 2007).

Using a qualitative descriptive design, Docherty, Miles, and Brandon (2007) explored healthcare providers' experience with palliative care in the pediatric acute care setting. The setting of the study included the intensive care nursery, the pediatric ICU, and the pediatric blood and marrow transplant unit from a large academic medical center in the southeast United States. A purposive sample of 17; 6 staff nurses, 4 physicians, 3 social workers, 3 advanced practice nurses, and 1 respiratory therapist participated in this study. Using a semi-structured and open-ended interview guide, several topics regarding palliative care were chosen by the researchers for discussion with the participants.

The researchers identified 3 themes from the study's findings which included: (1) palliative care as an added dimension in the illness trajectory, (2) palliative care moves away from curative treatment, and (3) professional issues. Interestingly the majority of the participants did not view palliative care as an element of care to begin at diagnosis and occur concurrently with curative care. The participants identified the transition from curative care to palliative care was difficult as not all members of the health care team acknowledged or supported the transition thus leading to feelings of discord for those involved (Docherty et al., 2007). The study's findings support the need for an interdisciplinary approach to pediatric palliative care beginning at diagnosis and continuing across the disease trajectory. Formal educational preparation to provide health care professionals with the necessary key principals of palliative care were underscored (Docherty et al., 2007).

Wright (2002) and Neilson (2010) explored the experiences of nurses providing palliative care to children and adults in the community setting. Using a qualitative, descriptive design with semi-structured interviews, Wright's (2002) study explored the understanding of the role of the district nurse (United Kingdom) in providing palliative care to adult clients dying in the home setting. The findings of this study emphasize that district nurses view themselves as: (1) having a critical role in providing care for dying clients in the home setting, (2) forming a relationship between the client and nurse which is seen as the standard through which all other care is provided, and (3) that the needs of the patient were identified and met, quality of care was subsequently enhanced which resulted from the personal relationship that had been established between the client and district nurse. The study's findings recognized the need for implementation of formal

structures (education and training) for the district nurses to support their clients (Wright, 2002).

Neilson (2010) conducted a qualitative study using in-depth interviews and a grounded theory approach for data analysis to explore the experiences of community children's nurses (CCNs) and children's palliative care nurses (CPCNs) (United Kingdom) who provided end-stage care to children at home. Twenty- two CCNs and eight CPCNs comprised the sample. The findings of this study identified that providing palliative care to the dying child at home occurs infrequently and each case is unique and offers its own challenges. Therefore, the CCNs and CPCNs expressed that it was difficult to maintain the necessary knowledge and skills to provide appropriate palliative care and to enhance the quality of life for these children (Neilson, 2010).

DeGraves and Aranda (2005) qualitatively explored the challenges and complexities that health care professionals (nurses, physicians, and social workers) encountered when caring for a child with cancer in which the focus has shifted from curative to end-of-life care. Data were collected using participatory group discussions and in-depth interviews. A content analysis was conducted in which three main themes of hope, uncertainty, and the interface between cure and palliation were extracted.

The findings by DeGraves & Aranda (2005) suggest hope was essential in helping the child and family with stressors associated with diagnosis and treatment and during disease progression. However, when hope was removed, this was difficult for the health care professionals as they reported feelings of abandoning families in their time of greatest need. Uncertainty surrounding the trajectory of the disease usually results in pursuit of curative efforts. Furthermore, when continuation of treatment is no longer

effective, this leaves little time for implementation of palliative services, thus leaving health care professionals feeling frustrated in the ability to provide quality of care. While hope is commonly considered an essential element in assisting the child and family through this difficult time, prognostic uncertainty could lead to palliative care needs being unmet. The study's findings advocated for a crucial need for additional research exploring the integration of palliative care occurring with curative care implemented at time of diagnosis. Palliative care support should be guided by the child and family's understanding of hope, experiences, beliefs and values across the disease trajectory (DeGraves & Aranda, 2005).

Lee and Dupree (2008) conducted a qualitative, descriptive study to explore and describe the experiences of a pediatric intensive care unit (PICU) staff that cared for dying children. The purpose of this study was to determine whether the responses obtained from the staff contained any indications of moral distress as defined in the literature. A semi-structured interview process was used with a convenience sample of 29 participants including nurses, physicians, and psychosocial support staff of a large multidisciplinary PICU. The researchers used a constant comparative method and content analysis to identify similarities and differences in the participant's responses. Overall the interviews yielded a positive voice regarding work satisfaction. Five major themes were identified from the interviews: (1) importance of communication, (2) accommodating others, (3) ambiguity about the use of technology, (4) sadness, and (5) emotional support (Lee & Dupree, 2008).

Numerous examples of caregiver suffering and distress were identified by the researchers. However, these responses were not characterized as moral distress because

they “did not meet the literature’s definition of moral distress but instead were similar to feelings of disquiet” (Lee & Dupree, 2008, p. 989). Additionally noted in this study was that providing end-of-life care can be emotional and challenging for healthcare professionals. The availability of emotional support when caring for dying patients is essential. This emotional support could lead to a decrease in healthcare suffering as well as sustain healthcare providers during this difficult process. The participants found the use of technology bittersweet, while providing opportunities for sustaining life, technology can be very invasive, and even when this technology is undertaken it may knowingly not yield a positive outcome. Clear, accurate communication and listening between staff as well as family members was recognized and appreciated as essential in this study by the participants to avoid misinterpretations (Lee & Dupree, 2008).

A descriptive study with a narrative analysis regarding oncology nurses’ perceptions about palliative care was conducted using focus groups by Pavlish and Ceronsky (2007). The purpose of this study was to elicit responses of nurses’ perceptions about the nature of palliative care. Thirty- three actively practicing oncology nurses participated in the focus group sessions. The findings of the study revealed that there was a considerable amount of agreement concerning the nurses’ descriptions of the nature of palliative care. Fourteen descriptors were identified by the researchers. In an attempt to examine the descriptors more carefully within and across the focus groups, the researchers constructed a data matrix to display specific quotes that exemplified each descriptor and then analyzed the differences and similarities between perceptions. This approach allowed the researchers to ascertain and comprehend the level of convergence

and divergence of the identified descriptors facilitating a deeper analysis of the data (Pavlish & Ceronsky, 2007).

Descriptors demonstrating convergence included: (1) palliative care is family focused, (2) palliative care is a continual process, (3) symptom management is important, and (4) palliative care attempts to enhance quality of life. Divergent descriptors identified were: (1) palliative care and oncology care are synonymous, (2) palliative care is the same as end-of-life care, (3) palliative care is opposite to curative treatment, and (4) there is lack of clarity regarding distinguishing characteristics of palliative care. Eight of the 14 descriptors identified by the researchers represented divergent viewpoints, thus indicating that discrepancies regarding palliative care are still common in clinical practice. Pavlish & Ceronsky (2007) stated that nurses in this study defined a complex healthcare system context which poses a challenge for the delivery of palliative care in the acute care setting. The participants of the study expressed their concerns regarding the time allotted by the healthcare system to patients in palliative care and their families. This “minimal time offered by the healthcare system to patients in palliative care and their families was viewed by the participants as a lack of respect for the journey that accompanies a life-limiting illness and the dying process” (Pavlish & Ceronsky, 2007, p.797).

A study by Weigel, Parker, Fanning, Reyna, and Brewer-Gasbarra (2007) investigated whether hospital nurses were apprehensive when caring for patients at the end-of-life. In addition, the researchers examined variables such as years of nursing experience, gender, work unit, and professional degree to identify if significance existed in relation to the nurses’ levels of apprehension. A single facility in the Midwest with 151 nurses representing seven adult units comprised the sample for this study. The

researchers administered the Professional End-of-Life Attitude scale (Weigel et al., 2007) which was a shortened version of the Physicians' End-of-Life Attitude scale (Levetown, Hayslip & Peel, 1999) and one in which the word "physician" was changed to "nurse" where applicable. The Physicians' End-of-Life Attitude scale (Levetown et al., 1999) had been validated against the Communication Apprehension Dying scale (CA- Dying scale) (Hayslip, 1986) which represents a measure of a layperson's communication apprehension. The CA-Dying scale assesses discomfort in communicating with dying patients and their families. The CA-Dying scale (Hayslip, 1986) produced a Cronbach $\alpha = .89$ and Pearson's $r = .75$ ($p < .01$) (Weigel et al., 2007)). The Professional End-of-Life Attitude scale (Weigel et al., 2007) produced three scores: (1) a communication apprehension score from the total of all 31 items, (2) a personal impact score from 13 items and (3) a professional impact score from 18 items. The personal impact score reflected responses to questions related to level of discomfort when caring for a dying patient and emotions that may arise when communicating with a dying patient and their family. The professional impact score was concerned with anxiety related to discussing advance directives and course of illness/treatment for the dying patient, delivering bad news, the ability to remain objective and the ability to control emotions while caring for dying clients (Weigel et al., 2007). Higher scores were indicative of greater apprehension. Length of clinical experience and personal impact score were significant, indicating that those nurses with less clinical exposure in caring for dying patients had higher personal impact scores ($r = -.19$, $p < .05$). All nursing units demonstrated a high level of apprehension when caring for dying patients, the differences between the nursing units

was minimal and depended on the nature and philosophy of the particular unit (Weigel et al., 2007).

McCloskey and Taggart (2010) conducted a qualitative study which explored the experiences of occupational stress from the perspective of nurses who provide palliative care to children in a region of the United Kingdom. The researchers were specifically interested in the experiences of occupational stress in the hospital setting, hospice setting, and community setting. A purposive sample of 18 nurses representing each of the previously mentioned settings participated in focus group discussions. A semi-structured interview guide composed of two sections was developed from an extensive literature search and the researcher's clinical experience to elicit responses from the participants.

The first section contained questions regarding what aspects (if any) of their work they found stressful. Section two of the interview obtained information regarding the impact of the previously identified stressors on the nurses. Four key themes were extracted and identified as: demands, relationships, maintaining control and support and roles (McCloskey & Taggart, 2010). Stressors (sleep disturbances, irritability, and inability to turn off the job) were common across all three settings studied (hospital, hospice, and community). Of particular interest in this study was the reporting of the ethical and emotional challenges experienced by the nurses as they attempted to "reconcile child and parental wishes which conflicted with personal and professional beliefs and values" (McCloskey & Taggart, 2010, p. 239).

2.3 Death Attitudes

Death is a fundamental aspect of life that should not be ignored and cannot be escaped. Clarke and Quin (2007) noted that providing palliative care to children and

families is multifaceted and becomes even more so of a challenge when end-of-life care must be initiated. Pediatric ICU nurses are pivotal in the care of dying children. However, the type of care provided to these children and their families by the pediatric ICU nurses may be affected by their own attitudes toward death (Rooda, Clements, & Jordan, 1999). According to Rooda et al. (1999) “Determinants of attitudes toward death and dying encompass not only cultural, societal, philosophical, and religious belief systems for giving meaning to death but also personal and cognitive frameworks from which individual attitudes toward death and dying are formulated and interpreted” (p. 1683).

Rooda et al., (1999) conducted a descriptive study which examined the possible relationship between demographic variables of nurses and their attitudes toward death and caring for dying patients. A total of 963 nurses were invited to participate via the institution’s internal mailing systems. Of the 963 invited to participate, 403 (42%) returned usable data. The researchers found that nurses with a greater fear of death demonstrated less positive attitudes toward caring for dying patients than did nurses with a lesser fear of death ($r = -0.34, p < 0.001$). In addition, those nurses who reported a tendency toward avoiding the issue of death had less positive attitudes than those who did not avoid the issue of death ($r = -0.37, p < 0.001$). Neutral attitudes toward death resulted in positive attitudes toward caring for people dying ($r = 0.22, p < 0.001$). Also of significance were nurses who considered death as an opportunity for a happy afterlife had more positive attitudes toward caring for dying patients ($r = 0.21, p < 0.001$). These researchers concluded the importance of the need for education regarding death attitudes and the influence of education regarding attitudes on the care of dying patients.

Frommelt (2003) conducted a quasi-experimental study (n= 49 in the intervention group, n = 66 in the control group) which examined the effect of an educational program on attitudes of undergraduate nursing students towards caring for terminally ill patients and their families with undergraduate nursing students. This semester-long educational program focused on death and ascertained if attitudes of these nursing students towards death changed after participating in the educational program. The study's findings reported significant positive changes in attitude of the nursing students toward caring for terminally ill patients in the intervention group and no significant change in attitude in the control group ($t = 7.283, p < 0.05$) (Frommelt, 2003).

Braun, Gordon, and Uziely (2010) examined the relationship between adult oncology nurses' attitudes toward death and caring for dying patients. The study was "cross-sectional, descriptive and correlational" (p.E44). A convenience sample was obtained through recruitment of participants at the Israeli Oncology Nurses Society annual meeting. Five hundred of the 600 members attended this conference. At registration each participant received a packet of information regarding voluntary and anonymous participation in the study from the research team. Of the 500 nurses in attendance, 170 returned the study questionnaire package with 147 of those returned fully completed, thus yielding a 34% return response rate. Participants were asked to complete the following questionnaires: Frommelt Attitude toward Care of Dying Patients (FATCOD) (Frommelt, 1991), the Death Attitude Profile –Revised (DAP-R) (Wong, Reker, & Gesser, 1994), and a demographic questionnaire developed by the research team. The FATCOD is a 30 item tool using a 5-point Likert scale to indicate respondents' attitudes toward caring for dying patients. The instrument consists of an equal number of

positively and negatively worded statements with response options of strongly disagree, disagree, uncertain, agree, and strongly agree. Positive items are scored one (strongly disagree) to five (strongly agree). Scores are reversed for negative items. Possible scores can range from 30–150 (Frommelt, 1991). The Death Attitude Profile – Revised scale is a 32 item scale that uses a 7-point Likert scale to measure respondents' attitudes toward death. The scale is comprised of five subscales to determine respondents' feelings of (a) fear of death—negative thoughts and feelings about death, (b) death avoidance—avoidance of thoughts of death as much as possible, (c) neutral acceptance—death is neither welcomed nor feared, (d) approach acceptance—death is viewed as a passageway to happy afterlife, and (e) escape acceptance—death is viewed as an escape from a painful existence (Wong et al., 1994). The demographic questionnaire developed by the research team sought information pertaining to gender, race, education, religiosity, questions on professional experience, exposure to dying patients and formal education in the care of dying patients (Braun et al., 2010).

Findings of the study reported that overall, the sample of nurses demonstrated positive attitudes toward caring for dying patients. However, nurses' attitudes toward caring for dying patients were significantly negatively correlated with death avoidance ($r = -0.42, p < 0.001$), fear of death ($r = -0.25, p < 0.01$), and approach acceptance ($r = -0.28, p < 0.001$). These findings indicated that those nurses reporting increased fear of death and death avoidance held less positive attitudes of caring for dying patients (Braun et al., 2010).

Analysis of the demographic information and the main study variables did not yield any significant correlations. However, two significant differences were reported by

the researchers. These included: (1) approach acceptance of death and degree of religiosity among nurses, greater acceptance of death and afterlife with those reporting religious and traditional degree of religiosity; (2) death avoidance and exposure to dying patients, those nurses who cared for fewer than five patients reported higher death avoidance scores. The findings of this study indicate that associations of fear of death and death avoidance when caring for dying patients still exist for some in this group of oncology nurses. The researchers concluded the importance of the need for education regarding the often unsaid issue of death. Additionally the researchers note the importance of accounting for personal attitudes toward death as well as religious and cultural beliefs and how these may influence patient care (Braun et al., 2010).

Lange, Thom, and Kline (2008) used a descriptive quantitative design and a convenience sample of 355 RNs to examine nurses' attitudes toward death and caring for dying patients in a comprehensive cancer center. In addition, the researchers explored if relationships existed between demographic factors and the nurses' attitudes toward death. Findings from the study yielded significant relationships among age, years of experience and previous experience caring for terminally ill patients with attitudes toward death and caring for dying patients. Older RNs with more years of work experience and prior experiences caring for terminally ill patients demonstrated more positive attitudes towards death and caring for this patient population. The need for improved nursing knowledge regarding palliative care is well-documented (Lange et al., 2008) and long overdue. The author suggests that now is the time to incorporate this information into nursing curricula.

2.4 Factors Influencing Provision of Palliative Care and Pediatric Critical Care

Nursing

Worldwide nursing shortages, an increased intensity of health care problems, and technologic advancement have confronted nurses with a variety of work-related stressors. Nurses working in the pediatric ICU are no exception. In general, nurses are working in a complex environment with rapid change, limited resources and sicker patients (Foglia et al., 2010). Working in the pediatric ICU brings additional workplace issues such as dealing with the impending death of a child, pain management, and providing family-centered care while handling and assisting diverse groups of caregivers involved in the child's life. However, the current nursing literature is lacking regarding information related to the nursing shortage and nursing turnover specific to the pediatric ICU (Foglia et al., 2010).

Workplace stress defined by Lambert (2008) as:

The physical and emotional outcomes that occur when there is disparity between the demands of the job and the amount of control the individual has in meeting those demands. When the challenges and demands of work become excessive, the pressures of the workplace exceed the worker's ability to handle them and job satisfaction turns to frustration and exhaustion (p.38).

Caring for critically ill children who may be in pain, suffering or nearing death and being a support for the family on a regular basis may become intolerable for the pediatric ICU nurse. This caring may be unbearable for the pediatric ICU nurse because of the uncertainty of the time span of these illnesses. These illnesses may continue over many years thus resulting in the subsequent development of possible job turnover.

Providing palliative care needs could further compound the incidence of workplace stress as palliative care should be encompassed at diagnosis and occur throughout the entire disease trajectory of the child (American Academy of Pediatrics, Committee on Bioethics and Committee on Hospital Care, 2000; Field & Behrman, 2003).

Foglia and Grassley (2010) conducted a phenomenological study to explore nurses' work experience within the context of their pediatric ICU nursing practice and the reasons which influenced their decisions to leave their practice. Purposive sampling was used to recruit participants with a final sample size of ten pediatric ICU nurses participating in the study. A demographic information form and semi-structured interview process served as data collection instruments.

Findings of the study revealed the participants' recollections of an overall pattern of unrelieved job stress as the major reason for leaving. However, three major interwoven themes with 11 associated subthemes were delineated and thus illuminated a deeper understanding of the factors that influenced the pediatric ICU nurses to leave their positions (Foglia et al., 2010). The three major themes identified were: nature of the job, insufficient resources and negative perceptions of managers/team leaders. *Nature of the job* in caring for infants and adults was different from that of adults. Three associated subthemes of (a) *high acuity of patients*, (b) *intense competency/skill set requirements*, (c) *caring for the families* were extracted from the data. Advances in technology, increased complexity of disease dynamics, atraumatic care, specialized medications and procedures of medication administration, complex procedures, as well as attention dedicated to growth and developmental level and subsequent needs of the child place additional demands on the pediatric ICU nurse. The inability to stay current with the

constant demands of changing technology and treatment modalities, along with the diverse and complexity of family needs and support led to loss of control, increased stress and job dissatisfaction. The participants expressed that practicing and caring for children in the PICU was further complicated as the themes of *insufficient resources and negative perceptions of management* yielded findings of inadequate staffing, extreme fatigue, long working hours, heavy workloads, and lack of appreciation and recognition by nurse managers. Thus, the only viable option identified by these nurses was to leave their current position (Foglia et al., 2010).

Bratt, Broome, Kelber, and Lostoco (2000) conducted a hallmark study exploring the influence of stress and nursing leadership on job satisfaction of pediatric ICU nurses. Using a cross-sectional survey design the researchers explored the influence of nurses' attributes, unit characteristics, and elements of the work environment on job satisfaction of a sample of 1,973 staff nurses in pediatric critical care units in 65 institutions in the United States and Canada. Additionally, the researchers attempted to determine stressors unique to pediatric critical care nurse. The sample of staff nurses was quite diverse in terms of education, experience and age.

Findings of the study included inverse significant associations ($r = - 0.37$ to $r = - 0.56$) between job stress and group cohesion, professional job satisfaction, nurse-physician collaboration, nursing leadership behaviors and organizational work satisfaction (Bratt et al., 2000). Additionally the researchers included open-ended questions on the survey to examine the perceived stressors of the pediatric ICU environment as experienced by the pediatric ICU nurses. A content analysis revealed three themes: issues concerning families, staffing needs and issues surrounding

death and dying. Unequivocally, dealing with families as the most frequent stressor of their work environment was delineated in the findings. The researchers concluded that job stress and nursing leadership behaviors were the most influential variables related to job satisfaction (Bratt et al., 2000).

Davies et al. (2008) conducted a survey using self-report questionnaires to assess the status and perceptions of barriers to end-of-life care in an academic children's hospital in northern California. The self-report questionnaire that examined staff member's perspectives to perceived barriers regarding end-of-life care was distributed to 698 providers. Sample characteristics reported in this particular study included responses from nurses and physicians of this institution. A total of 240 providers responded with nursing (n= 117) and physicians (n = 81) producing an 83% response rate of the surveys returned. The remaining 42 surveys were completed by members of other disciplines and therefore not included in these findings.

The findings revealed that the participants identified the following four barriers either frequently or almost always occurring when providing palliative care: (1) uncertain prognosis, (2) family not ready to acknowledge incurable condition, (3) language barriers, and (4) time constraints. These barriers were perceived by the participants to interfere with their ability to provide optimal pediatric palliative care, and thus the inability to provide optimal quality of care for the child with a life-limiting illness (Davies et al., 2008).

Pediatric ICU nurses may enter into and subsequently develop caring relationships with the child and family for whom they are caring regardless of one's personal experiences with death. Rashotte, Fothergill-Bourbonnais, and Chamberlain

(1997) utilized a Heideggerian phenomenological approach to explore and describe the grief experience of pediatric ICU nurses once their patient has died. The researchers articulated that if these nurses were unable to grieve effectively, “this could possibly affect future crises, increase work stress, erode the nurse’s self-esteem as well as patient and family care relationships and staff relationships” (p. 372). To facilitate understanding of the lived grief experience of the pediatric ICU nurse, a nonprobability purposive sampling design was used. Demographic information was obtained prior to a guided interview with open-ended questions to enable investigation into the phenomenon of grief.

Rashotte et al. (1997) reported eight themes were extracted from the data. The theme of hurting “delineated how these pediatric ICU nurses reacted to the death of a child for whom they had cared” (p.377). The responses described in this theme appeared to be influenced by numerous factors such as the context of the situation, the experience level of the nurse, visibility of parental distraught and level of attachment to the child. The two themes of nature of the nurse-family unit relationship and dissonance “described the contextual factors which influenced the nurses’ grief response” (p.377). The participants described greater grief when they had made a connection with the child as the child had become significant in their personal lives. Additionally, grief responses were intensified when the nurses were not able to resolve their personal beliefs concerning death with the reality of how the death had actually occurred. The remaining five themes related to how these nurses managed their grief and were identified as: self-expression, self-nurturance, termination of relationship activities, engaging in control-taking activities and self-reflection. The participants cited the use of public and private

domains to allow for expression of feelings of grief, the importance of closure to allow one the ability to reinvest in future relationships and the creation of limits to balance one's professional and personal life (Rashotte et al., 1997). The findings of this study implicate recognizing the importance of the uniqueness of the pediatric ICU nurses experience with death while being sensitive to coping needs and offering choices to the individual nurse at the time of the child's death.

2.5 Summary

The experience of providing pediatric palliative care is unequivocally multifaceted, unique, and very different from adult palliative care. The journey to the end, which often occurs in the pediatric ICU, is frequently stressful and demanding for all involved (Jones et al., 2007; Levetown et al., 2010). Each situation of pediatric palliative care involves challenges for the pediatric ICU nurse and is often influenced by such things as symptom management, family dynamics, lack of multidisciplinary support, lack of management support, emotional issues, and ethical issues. Maintaining and retaining skilled compassionate nurses caring for critically ill children requiring palliative care may present a challenge for healthcare organizations as these caregivers are exposed to intimate encounters of children's suffering (Clarke & Quin, 2007; Neilson, 2010).

The literature is lacking regarding the perspectives of the pediatric ICU nurse providing palliative care to the child with a life-threatening or life-limiting illness and their families. Pediatric ICU nurses should be committed, supported and competently prepared in all aspects and situations to care for dying children to possibly improve the quality of care and provide the safest care which enhances the lives of this vulnerable population. Increasing nursing's knowledge base by exploring and understanding the

pediatric ICU nurses' perspectives regarding palliative care could enhance numerous aspects of pediatric palliative care. These aspects may include: (1) effective communication, (2) comfort, (3) mitigation of pain and other symptoms, (4) alignment of care with the child and family's goals, (5) maximizing growth and development, and (6) transition from curative care to end-of-life care, (7) as well as job satisfaction, (8) possible reduction of stress, and (9) development of coping strategies for the pediatric ICU nurse which may allow for a positive integration of work experiences with life experiences.

CHAPTER THREE

METHODOLOGY

3.1 Purpose

Phenomenological research is concerned with the study of the lived experience, the explication of phenomena as they present themselves to consciousness, the study of essences and the description of the experiential meanings we live as we live them (Van Manen, 1990). Phenomenology, specifically hermeneutic phenomenology, is an appropriate qualitative method for this study of inquiry as it is an approach which seeks to explore and understand the meaning of the individual's experience (Cohen et al., 2000). In this study, the aim was to discover and unfold the essence of pediatric ICU nurses' experiences in providing palliative care to children with life-threatening or life-limiting illnesses.

3.2 Methodological Framework

Phenomenology.

Phenomenology recognizes that each individual's experience is unique and it is the meaning given by the individual to the experience that allows us to develop an understanding of the essence of the phenomenon. According to Van Manen (1990): Phenomenology is aimed at gaining a deeper understanding of the nature or meaning of our everyday experiences. Anything that presents itself to consciousness is potentially of interest to phenomenology, whether the object is real or imagined, empirically measurable or subjectively felt. Consciousness is the only access human beings have to the world; or rather it is by virtue of being conscious that we are already related to the world. Thus all we can ever know must present itself to consciousness. Whatever falls

outside of consciousness therefore falls outside the bounds of our possible lived experience (p. 9).

Historical perspective.

The word *phenomenology* first articulated in the 1760s by the world renowned German scholar and philosopher Immanuel Kant, has a multiplicity of meanings and has been an important field of inquiry in numerous disciplines. Phenomenology was introduced as a new philosophy at the beginning of the 20th century and evolved into a significant movement throughout the century. The understanding of phenomenology continues to be dynamic and evolving in present day. The key contributors to this Phenomenological Movement include: Brentano and Stumpf, of the preparatory phase; Husserl and Heidegger, of the German phase and Marcel, Sartre and Merleau-Ponty, of the French phase (Spiegelberg, 1984). Numerous phenomenological philosophies exist, thus it is important to appreciate the underpinnings of the phenomenological approaches as well as the methodological implications for research. Accordingly, a fundamental understanding of the phenomenological approaches and methodological implications for research would enhance and provide for rigor as well as accurate interpretation of the phenomenon of interest. Moreover, what is common to all of these phenomenological approaches is “a focus on exploring how human beings make sense of their experience and transform experience into consciousness, both individually and as shared meaning” (Patton, 2002, p. 104). An overview of the philosophical approaches of Edmund Husserl and Martin Heidegger will be presented as these approaches have significantly influenced and are frequently referenced in the hermeneutic phenomenological nursing research (Walters, 1995).

Husserlian phenomenology.

Edmund Husserl, often noted as the founder of phenomenology, developed a philosophical approach grounded in subjective candidness. Husserl believed that subjective information, such as a description of the lived world, should be considered important to researchers who were seeking to understand human motivation as human actions are influenced by what people perceive to be real. People often carry on with the business of daily life without critical reflection of their daily lived experiences. Husserl believed that a descriptive phenomenological approach would assist in revealing these essential components of the lived experience, the discovery of meanings and essences in knowledge (Lopez & Willis, 2004). However, these components of the lived experience are intertwined with subjective and objective knowledge. Husserl believed the challenge to the human researcher was to describe these experiences as they were, and enter into consciousness to be understood in its meanings and essences in the light of intuition (Moustakas, 1994).

The development of Husserl's philosophy of phenomenology is often divided into three phases; pre-phenomenology, phenomenology as a limited epistemological enterprise and finally transcendental phenomenology which is based on epoche, intentionality of consciousness and eidetic description (Richards & Morse, 2007). Although there were distinct differences noted throughout the development of his phenomenological philosophy, Husserl's idea of rigorous science was constant throughout his career and he believed it was the basic concepts of phenomenology which provided that rigor (Cohen, 1987). The basic concepts for Husserl include: (a) essence,

(b) life-world, (c) intentionality, (d) intersubjectivity, (e) intuition, (f) phenomenological reduction.

Essence.

Essence is defined as the “whatness” of things as opposed to the ‘thatness’ of things, i.e., their existence” (Spiegelberg, 1984, p.743). Essences are “elements related to the ideal or true meaning of something that is, those concepts which give understanding to the phenomenon of interest” (Streubert & Carpenter, 2011, p. 75). It is the essences which comprise the consciousness and human world. These essences, which are considered the basic unit of common understanding of the phenomenon of interest, have been found to occur alone or in relationship to one another (Koch, 1995; Streubert & Carpenter, 2011) Thus, the essence (consciousness) is the reality of the phenomenon of interest.

Life-world.

Life-world or lived experience is another meaningful aspect of Husserlian phenomenology. Life-world has been described as the “world of immediate experience,” (Van Manen, 1990, p. 9) that which already exists; “reality which we take for granted” (Koch, 1995, p.828). Life-world is the everyday experience(s) which is influenced and subsequently interpreted by the individual and is based on one’s values, beliefs and assumptions and that which we often fail to notice. Husserl asserts that it is the consciousness of these experiences and how the consciousness determines the meaning of the experience that needs examined (Koch, 1995).

Intentionality of consciousness.

Intentionality of consciousness is often considered the core of Husserl's phenomenology and is understood as the direction of consciousness toward understanding the world (Sadala & de Camargo Ferreira Adorno, 2002). Intentionality refers to the "internal experience of being conscious of something; thus the act of consciousness and the object of consciousness are intentionally related" (Moustakas, 1994, p. 28). According to Husserl, intentionality is the fundamental structure of consciousness (Spiegelberg, 1984).

Consciousness, through intentionality, is necessary so that meaning can be given to a group of actions/objects. Consciousness is the instrument which attributes meaning to actions/objects. According to Husserl, it is imperative to determine the meaning of these actions/objects as for without meaning how would the essence of the action/object be discovered (Sadala & de Camargo Ferreira Adorno, 2002)?

Intersubjectivity.

Intersubjectivity is another central concept of transcendental phenomenology. This concept asserts a plurality of subjectivities making up a community share in a common world (Spiegelberg, 1984). According to Husserl (1982), an intersubjective experience plays a fundamental role in our constitution of both ourselves as objectively existing subjects and other experiencing subjects. An intersubjective experience is an empathic experience; it occurs in the course of our conscious acknowledgment of intentional acts to other subjects. This experience is where the organized subjective worlds of two people intersect with each other in an attempt to understand each other's subjective world, in other words attempting to place oneself into

another person's situation. The subjective world is comprised of the organization of feelings, thoughts, values, beliefs, principles, theories, illusions, distortions and whatever else will assist or hinder that person (Creswell, 2009). Additionally, even when there is intersection of the two subjects' organized worlds, the amount of knowledge obtained is only that which has been told by the other person.

Intuition.

Intuition is instinctive and unconscious knowing arrived at without deduction, it presents itself. Intuition is the underpinning for the derivation of knowledge regarding the human experience. For Husserl, intuition is essential to describe whatever presents itself and is regarded as "the presence to consciousness of an essence" (Moustakas, 1994, p. 33). Therefore, it is when the ability to withhold one's natural attitude and truly consider something in its bare presence that the essence can be fully appreciated.

Phenomenological reduction.

Phenomenological reduction is an essential process in transcendental phenomenology. The goal in phenomenological research is to analyze the intentional experiences of consciousness and to subsequently understand the meaning given to the experience and to arrive at the essence of that meaning (Sadala & de Camargo Ferreira Adorno, 2002). Phenomenological reduction is the means that will facilitate obtaining a reliable understanding of the meaning and subsequent essence. Phenomenological reduction begins with setting aside any personal beliefs or knowledge and remaining unbiased concerning the phenomenon of interest: this process is known as bracketing or *epoche*. *Bracketing or epoche* must be constant and ongoing to ensure rich and pure

descriptions of experiences. This process of bracketing or epoche does not eliminate all presuppositions or all reality. For Husserl, it was meant to reduce the natural attitude, “the biases of everyday life, the knowing of things in advance from an external base rather than from internal reflection and meaning” (Moustakas, 1994, p.85). Moreover, Husserl believed following this process would provide a sufficient reduction to yield a focused understanding of the phenomenon of interest.

Therefore, Husserl’s phenomenology has come to mean that through phenomenological reduction the learned assumptions or natural attitude are put into abeyance thus allowing refining of consciousness. This process allows for the acts of consciousness to be given meaning and subsequently transformed into essence (Yegdich, 2000).

Heideggerian phenomenology.

The basic difference between Husserl and Heidegger’s fundamental a phenomenological purpose is that with Husserl, the focus is on consciousness, while for Heidegger, the focus is on the fact of the Being (Spiegelberg, 1984). An overview of Heideggerian phenomenology is presented.

Martin Heidegger, an established scholar and student of Husserl’s challenged several assumptions of how Husserl’s phenomenology leads to a meaningful inquiry (Lopez & Willis, 2004). Thus, Heidegger modified and built upon Husserl’s work and developed ideas which comprised an interpretive research tradition and an approach of existentialism which was concerned with Being and time (Cohen, 1987).

A central tenet of Heidegger’s approach is to understand the meaning of Being which Heidegger referred to as *Dasein*:

Dasein is an entity which does not just occur among other entities. Rather it is ontically distinguished by the fact that, in its very Being, that Being is an issue for it. But in that case, this is a constitutive state of Dasein's Being, and this implies that Dasein, in its Being, has a relationship towards that Being—a relationship which itself is one of Being. And this means further that there is some way in which Dasein understands itself in its Being, and that to some degree it does so explicitly. It is peculiar to this entity that with and through its Being, this Being is disclosed to it. Understanding of Being is itself a definite characteristic of Dasein's Being. Dasein is ontically distinctive in that it is ontological (Heidegger, 1962, p. 12).

Analysis of Heidegger's study of 'Being' is achieved by consideration of the everyday existence of people in and of their world, as opposed to subjects in a world of objects. Thus, individuals' realities are influenced by the world in which they live (Lopez & Willis, 2004; Walters, 1995). Heidegger stresses the importance of the permanent unity of person and the world, in which the person is fixed in their world and makes choices based on the historical, political and social contexts which subsequently shape and organize their experiences (Lopez & Willis, 2004).

Heideggerian phenomenology is defined as:

An analysis by which the meaning of the various ways in which we exist can be translated from the vague language of everyday existence into the understandable and explicit language of ontology without destroying the way in which these meanings manifest themselves in our everyday lives (Gelven, 1989, p.42).

Heidegger also puts forward the concept of 'pre-understanding' to describe

the meaning and organization of a culture including language and practices which are considered a structure of our 'being in the world' (Koch, 1995, p. 831). Heidegger further emphasized that it is impossible to rid the mind of the background of these understandings, it is not something that we can eliminate, set aside or put in abeyance as it exists with us in the world: these pre-understandings can only be corrected and modified (Koch, 1995). For Heidegger, meaning is found because one is constructed by the world while one is simultaneously constructing the world based on their personal knowledge and experiences. Therefore, it is the interpretation of the meaning of the individual's experiences of Being in the world and how those meanings influence the choices the individuals decide upon which is foundational for the interpretive research tradition. To interpret and understand the meaning of the experience, Heidegger uses the concept of the hermeneutic circle in which there is a shifting from the parts to the whole to the parts to facilitate an accurate understanding of the experience being investigated. This dialectical process deepens the understanding of the whole through increased knowledge of the parts with the intent to achieve a sensible meaning of the experience (Polifroni & Welch, 1999).

The descriptive phenomenological approach is beneficial to uncover essences of phenomenon while the interpretive phenomenological approach is useful to examine the meaning within contextual experiences. While these phenomenological approaches represent critical differences, each phenomenological approach can contribute to nursing knowledge development.

3.3 Research Method

Hermeneutic phenomenology, as delineated by Cohen, Kahn, and Steeves (2000), was the research method utilized in this study. Hermeneutic phenomenology is a combination of interpretative (Heidegger) and descriptive (Husserl) elements. This combination of elements will allow for the study of how people “interpret their lives and make meaning of their experiences” (Cohen et al., 2000, p.5). This study focused on understanding the essence of the pediatric ICU nurse’s experiences within the context of providing palliative care to children with life-limiting illnesses.

3.4 Research Setting

The study took place in a non-free standing children’s hospital in northeastern United States. The non-free standing children’s hospital provides tertiary level care for children from birth through adolescence. The children’s hospital consists of two 18 bed medical-surgical units, a 43 open bed neonatal ICU and a 12 bed pediatric ICU. The pediatric ICU served as the study setting.

A choice of the following locations for conducting interviews was given to the participants: (1) the pediatric ICU consultation room, (2) the pediatric ICU community conference room, (3) a private office located in an adjacent building to the medical center, or (4) a place of convenience determined by the participant. The participants were offered these choices for their convenience during the interview process. All of these locations offered familiarity, privacy, confidentiality and ease of access to the participants.

3.5 Procedure for Protection of Human Subjects

Permission to conduct this study was sought through Duquesne University's Institutional Review Board (IRB), Pittsburgh, Pennsylvania as well as the study setting's IRB. This study met the criteria as an expedited review for the following reasons: (1) it contains audio recordings, individual's characteristics when considering the subject's own behavior which includes perception, cognition, motivation, socio-cultural beliefs and language for purposes of research. Once permission was obtained from Duquesne University's IRB, permission from the study setting's Nursing Research Council and IRB was obtained. To protect the human subjects of this study, data collection included informing participants of their rights as well as protecting participants' rights during this study. Prior to signing the informed consent (Appendix B), the participants were made cognizant that there were no risks anticipated by participating in this study. The informed consent outlined the researcher's and participant's duties. Reading and signing the informed consent indicated their willingness to participate in the study and an understanding of the participant's rights. Each participant was offered a copy of the signed consent. Participants were respected and treated with dignity throughout the study. The participants could withdraw from the study at any time for any reason and withdraw from the study did not affect their employment either in a positive or negative manner.

Any questions by the participants regarding the study were addressed prior to beginning the interview process as well as during the interview process. The interview process began with the completion of the Demographic Questionnaire (Appendix A) and continued with use of the semi-structured interview questions and probes. Participants

were reminded that they would be audiotaped and occasional written notes (field notes) would be taken by the researcher during the interview process. The interview process with audiotaping then began. If questions asked during the interview process stimulated any difficulties for the participants, they had been reminded they could choose not to answer that question and could move to the next question, take a recess from the interview process or withdraw from the study at any time. Emotional support was provided by the researcher. If additional support was needed by any participant, a referral to a local counseling agency was available to the participant. The cost of the counseling appointment was waived as the licensed counselor had volunteered this service to the participants of the study, if necessary. Respect for the participant's welfare took precedence over research. Participants were informed that the audiotape recorder could be turned off anytime during the interview if they did not wish to have certain comments recorded. In addition, the participants were told that all information obtained would remain confidential. The participants had the right to withdraw from the study and could do so at any given time without consequences. Participation in this study was voluntary and participation or lack of participation in this study did not positively or negatively affect their employment or advancement. Anonymity of the participants was maintained by the use of a pseudonym chosen by the researcher to avoid the use of names and identifiers during audiotaping and subsequent transcribing of data. All written materials, audiotaped interviews and consent forms are currently stored in a locked file cabinet in the researcher's home and will remain there for five years. The participant's responses to the interview questions and demographic information questionnaire appear as an aggregated summary of results as all data has been de-identified.

Expert transcription services were sought and obtained. Once transcription services were obtained, the importance of confidentiality regarding the audiotapes and verbatim transcriptions was reviewed with the transcriptionist. The transcriptionist signed a confidentiality agreement (Appendix E) to ensure privacy of the participant's responses. All materials from this study will be destroyed at the end of five years.

3.6 Sample for the Study

Sampling strategies utilized for qualitative studies are generally concerned with selecting participants who can illuminate and provide rich information to maximize the understanding of the phenomenon. Purposive sampling is a sampling strategy which can yield information-rich data as participants are purposefully selected based on their knowledge of the phenomenon of interest. Maximum variation sampling, a specific purposive sampling strategy, was used in this research study to capture and describe central themes that may emerge across participant variations (Patton, 2002). The purpose of maximum variation sampling is the discovery of "any common patterns that emerge from the participant variation will be of particular interest and value in capturing the core experiences and central, shared dimensions of the phenomenon" (Patton, 2002, p.235), in other words, ensuring participants with various backgrounds are represented in the sample to capture diverse perspectives regarding the phenomenon of interest. The goal of most qualitative studies is to develop an understanding of the phenomenon through information-rich cases described by participants (Byrne, 2001; Patton, 2002). Therefore, in qualitative research most samples are nonrandom and small in size as the intent is to maximize information of a phenomenon of interest/setting not generalize findings to a population. According to Patton (2002), "sample size depends on what one wants to

know, the purpose of inquiry, what is at stake, what will be useful, what will have credibility, and what can be done with available time and resources” (p. 244). Thus, there are no steadfast rules for sample size in qualitative research.

Inclusion criteria for the participants of the study was as follows: (1) a staff RN, any educational level, working in the PICU for at least 18 months (as the first 6 months are usually an orientation process), (2) willingness to describe their experiences of providing palliative care to children with a life-threatening or life-limiting illness, and (3) willingness to provide demographic data and to be interviewed twice. To enhance diversity of the participants an attempt to choose participants with respect to diversity in age, gender, educational level, years of experience and personal experiences with loss was conducted. The previously mentioned information was obtained and analyzed using information from the Demographic Questionnaire (Appendix A). Each participant was asked to complete the questionnaire at the beginning of the first interview process.

Data collection and data analysis occurred concurrently during the study to attain and maximize information regarding the phenomenon of interest. Purposive sampling continued until no generation of new information was obtained from the participants; this is referred to as informational redundancy and saturation (Lincoln & Guba, 1985).

3.7 Recruitment of Participants

Recruitment of participants began after approval from Duquesne University (Appendix B) and the study setting’s Institutional Review Boards (IRB) (Appendix C). The pediatric ICU staff of the study setting is an all RN staff, comprised of approximately 35 people with a fairly close ratio of 1:1 males to females. The researcher purposefully invited those participants who indicated an interest in the study

and were open to discussing their experiences of providing palliative care to children with life-threatening or life-limiting illnesses. The PICU management team announced the research study at unit meetings and the same information was posted in the staff break room (Appendix F). The interested participants met with the researcher who provided greater detail regarding the following to the potential participant: (1) purpose of the study, (2) the interview process, (3) time commitment necessary to complete the study, and (4) an opportunity for additional questions. Possible benefits to the participant may include the opportunity to reflect on this topic with an interested nurse and possible satisfaction in determining useful ways to meet the needs of as well as provide and improve care to children with life-limiting illnesses was discussed. An agreed upon date, time and location for the interview process was determined with the potential participant.

It is anticipated that if the researcher receives funding for this study, a monetary appreciation in the form of a \$20.00 gift card will be presented to each participant at the end of the follow-up meeting for their time and commitment given to the study.

3.8 Data Collection Instruments

Three instruments were used for data collection in this research study: a 9 item researcher developed demographic questionnaire (Appendix A) and a semi-structured interview guide (Appendix D) with probes and written field notes. The use of a semi-structured interview process was chosen as it provides greater breadth and richness in the data and allows informants freedom to respond to questions and narrate their experiences (Ajjawi & Higgs, 2007). Written field notes were taken throughout each interview to capture any details and observations of the participant and physical ambience which could not be determined from the audiotape. Field notes may add invaluable

information to the construction and interpretation of the data (Cohen et al., 2000). In addition, probes (Appendix D) were used to assist with clarification and to obtain possible additional information richness.

3.9 Procedure for Data Collection

Data collection involved one interview, one follow-up meeting per study participant and the use of field notes. The first interview began once informed consent had been discussed and obtained. The first interview processes lasted from 45 minutes to one hour and 17 minutes. Opportunities were provided for the participants to discuss questions concerning the consent form as well as any questions that arose throughout the interview process. The participants were reminded that the entire interview process was being audiotaped and the researcher would be taking written field notes sporadically during the interview process. At the beginning of the first interview, the participant was asked to complete a Demographic Questionnaire (Appendix A). It is anticipated that completion of this questionnaire by the participants would take approximately five minutes which was then followed by the interview process. A follow-up meeting to review the interpretation of the participant's description of their experience was scheduled at a time of convenience for the participant; this meeting lasted approximately 10 – 15 minutes for all participants. The follow-up meeting provided an opportunity for the participants to review their transcribed transcript for accuracy of interpretation of their experience by the researcher and to add any additional information they may have thought of since the initial interview. A \$20.00 gift card to a local eatery of the participant's choice was given at the completion of the follow-up meeting. To ensure consistency, the researcher conducted all interviews and follow-up meetings with the

participants. Data was collected over the time period of October 2012 through December 2012.

The goal for the hermeneutic phenomenological researcher is the ability to report the findings of the phenomenon as they are encountered and documented in the field text rather than as the researcher would have them to be (Cohen et al., 2000). In qualitative research, the researcher is considered the instrument thus it is expected that researchers will make sincere efforts to identify and set aside their beliefs and opinions to more accurately describe the informant's experiences (Ahern, 1999). This process is known as bracketing and is regarded as the first step of inquiry in hermeneutic phenomenology and represents the start of an ongoing process of critical reflection throughout the study (Cohen et al., 2000). Bracketing is an iterative process used to identify and set aside the researcher's preconceptions concerning the phenomenon of interest which will facilitate the researcher's ability to understand the essential lived experience (Cohen, 1987; Lopez & Willis, 2004). This process allows for the researcher to be in an enhanced position to approach the topic honestly and openly (Streubert & Carpenter, 2011) thus optimistically reducing personal bias. Remarkable differences exist in bracketing between Husserlian and Heideggerian phenomenological philosophies. Husserl espoused that it is necessary for the researcher to put aside from mind all prior expert knowledge and personal bias of the phenomenon of interest to fully appreciate the essential lived experience as perceived by those being studied (Lopez & Willis, 2004). Conversely, Heidegger emphasizes that presuppositions and expert knowledge are valuable to the inquiry and it is not possible to rid one's mind of personal biases (Koch, 1995). Accordingly, presuppositions and expert knowledge are considered essential and are embedded within the interpretive process.

The researcher engages in an ongoing process of self-reflection in interpretive phenomenology. However, the researcher is called upon to critically examine their personal knowledge and presuppositions and the effects that knowledge or those presuppositions may have on the phenomenon of interest being studied (Laverty, 2003). The researcher attempted bracketing by audiotaping her responses to the interview questions prior to data collection and used Ahern's (1999) tips as applicable for reflexive bracketing to support the process of critical reflection throughout the research study. Ahern's (1999) tips include: (1) issues "taken for granted" (p. 408) in this study, (2) clarification and acknowledgement of personal value system, (3) areas of potential role conflict, (4) gatekeeper's interest and influence, (5) awareness of personal feelings, (6) unexpected findings during data collection and analysis, and (7) methodological issues.

Interview process.

Prior to data collection, the researcher attempted to bracket any presuppositions concerning the phenomenon of study as previously stated. After choosing a location of comfort for the interview process and informed consent was discussed and obtained, the interview process with audiotaping began using the semi-structured interview questions. The goal of the interview process in hermeneutic phenomenology is to elicit narrative data in an informal manner similar to an everyday conversation. A retrospective approach was used as the participants recruited had had the experience of providing palliative care to children with life-limiting illnesses and were asked to reflect and highlight on that experience in the interview process. Information was exchanged between the participant and researcher in a relaxed atmosphere with the

emphasis on the researcher accurately listening to the participant rather than guiding the conversation (Cohen et al., 2000).

The open-ended questions of the semi-structured interview focused on eliciting the experience of providing palliative care through the perspective of the pediatric ICU nurse and revealing of the essence of the phenomenon as well as an in-depth understanding of the contextual factors associated with the experience. The probe questions were used to initiate further responses and provide clarification of meanings as needed. The initial interview, an in-depth audio recorded interview, lasted anywhere from 45 minutes to an hour and 20 minutes. An audiotaped follow-up meeting, which allowed the participants to ask any remaining questions, comment on the accuracy of the researcher's interpretation of their experience, and provide additional descriptions of the experience of inquiry leading to more information-rich data lasted approximately 15 - 30 minutes for each participant. Field notes, specifically descriptive notes, were taken to provide rich detailed objective accounts of the environment during both interviews. Field notes enabled the researcher to record the aspects of the interview which are not usually detected from an audiotape interview. These aspects included the location of the interview the participant chose, body language of the participant, demeanor of the participant and environmental distractions. Field notes provided the researcher the ability for reflection, self-evaluation and further discovery of details that surfaced once the tape recorder was turned off (Cohen et al., 2000).

3.10 Procedure for Data Analysis

Data analysis in hermeneutic phenomenology is typically concurrent with data collection and continues until completion of the study to identify any areas of further scrutiny of experiences with the participants. The purpose of data analysis was to accurately interpret the meaning of the participant's lived experience (Cohen et al., 2000). Therefore, all audio-taped interviews of the participants were transcribed verbatim and accuracy of the interpretation was verified by the researcher. Transcripts were read several times by the researcher to gain a sense of the interview experience as a whole.

Additionally, the researcher's descriptive field notes from the initial interview and follow-up meeting were included in the data analysis procedure. The follow-up meeting afforded an opportunity for the participants to provide additional information-rich narratives due to having time to reflect on their lived experience (Cohen et al., 2000). NVivo 9 (QSR International, 2010) [Computer software] qualitative data manager was used to manage the data analysis. Once all transcriptions were completed, the data was entered line by line into the NVivo (QSR International, 2010) [Computer software].

Analysis of data was based on the application of the hermeneutic phenomenological analysis as delineated by (Cohen et al., 2000). This approach is based on the following phases: (1) immersion in the data; (2) data transformation or data reduction; (3) thematic analysis; (4) writing and rewriting (Cohen et al., 2000).

Immersion in the data.

The goal of this phase is for the researcher to develop familiarity with the data. This phase is comprised of organizing data into texts, iterative reading of texts, identification of essential characteristics in the data and preliminary interpretation of texts to facilitate coding during analysis.

Data transformation or data reduction.

The researcher must determine between relevant and non-relevant data without losing the meaning of the interview. The researcher can reorganize the transcribed data according to similarities of the same topic or exclude data which digresses from the topic of interest (Cohen et al., 2000).

Thematic analysis.

This phase of analysis requires the researcher to have gained an understanding of the overall text. Once the researcher has obtained an understanding of text, the researcher will attempt to identify themes in the transcripts by examining the document line by line. Passages of the data will be underlined and labeled with tentative theme labels (Phillips & Cohen, 2011). Themes will be compared within and between transcripts.

The use of the hermeneutic circle (Figure 1) strategy during this phase of analysis will be used to enhance the understanding and interpretation of the data collected. This process is viewed as “movement between parts of the text (data) and whole text (evolve an understanding of the phenomenon) each giving meaning to the other such that the understanding is circular and iterative” (Ajjawi & Higgs, 2007, p.622). Through the use of reflective awareness, this circular and iterative process allows for consideration and understanding of the smallest statements in terms of the largest context and affords a

more in-depth analysis of the data, allowing extracted data to remain open to alternative interpretations and understanding the temporality of truth. Understanding of the phenomenon of interest thus is extracted from the process of dialectical examination between the researcher and text of the research (Bontekoe, 1996).

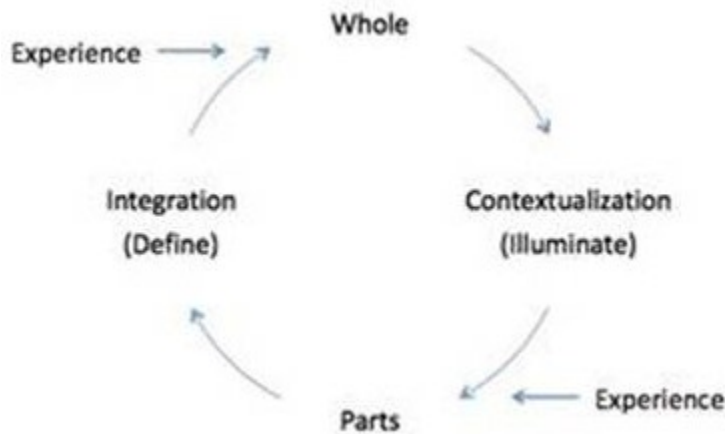


Figure 1. From *Dimensions of the Hermeneutic Circle* (p.2), Bontekoe, R., 1996, Atlantic Highlands: New Jersey. Reprinted with permission.

Writing and rewriting.

According to Cohen et al. (2000) this reflective writing process is the movement from identification and comparison of themes to a coherent picture of the whole. As insight and understanding of the meanings of the participants' experiences are obtained, "the understandings should be summarized as written memos which serve to document the transformation of the field text to narrative text" (Cohen et al., 2000, p.82). Thus illumination and illustration of the phenomenon of interest is extracted.

3.11 Establishing Rigor or Trustworthiness

Qualitative researchers use the concept of rigor or trustworthiness to evaluate study findings. Establishing trustworthiness of a qualitative study can be accomplished by incorporating various strategies into the data collection and data analysis process. In most qualitative studies four criteria for trustworthiness merit attention and include: (1) credibility (analog to internal validity), (2) dependability (analog to reliability), (3) confirmability (analog to objectivity), and (4) transferability (analog to external validity), (Patton, 2002). Numerous strategies related to the above criteria were utilized to promote trustworthiness of this study.

Credibility.

Credibility refers to an evaluation of whether or not the research findings are a truthful interpretation of the data drawn from the participant's original data (Lincoln & Guba, 1985). To address the issue of credibility the techniques of *member checking* and *peer debriefing* were used to enhance credibility (Streubert & Carpenter, 2011). Member checking involved taking the study's findings back to each participant and asking them to verify the accuracy of the interpretation regarding their experiences by the researcher. This was accomplished with a follow-up meeting 2 – 3 weeks after the initial interview which allowed for the participants to comment on the accuracy of the interpretation of their experience by the researcher and add any additional information. Peer debriefing is the strategy in which there is recruitment of a colleague(s) with sophistication in qualitative research but without extensive expertise in the phenomenon of interest or personal interest in the study's findings (Strubert & Carpenter, 2011). This was completed with the researcher's dissertation committee. *Reflexive journaling and*

bracketing was also conducted by the researcher to further enhance credibility. This included regular journal entries by the researcher regarding the manner of the interactions and reactions that arose during the interview process. These entries were read and reflected on by the researcher regularly to reduce the likelihood of personal beliefs influencing the data collection and data analysis process.

Dependability and Confirmability (Auditability).

Dependability represents the truth and consistency of the study's findings. Confirmability signifies the process in which the researcher demonstrates how the interpretations of the study have been reached (Koch, 1994). To address dependability and confirmability in this study, an audit review of the research methods utilized was conducted by the researcher's dissertation committee. The audit process should clearly demonstrate the process engaged in to reach the study's conclusion. According to Patton (2002) there are two components to the audit of review (1) the dependability judgment which examines the methodological process and (2) the confirmability judgment which examines the product (data) results. The auditor had the opportunity to thoroughly examine the original de-identified transcripts, data reduction and data analysis documents, field notes, comments obtained from member checking, and the text of the dissertation. The researcher's dissertation committee approved the dependability and confirmability of the study.

Transferability or Fittingness.

Transferability or fittingness is the likelihood that the study's findings will have meaning to others in similar situations (Streubert & Carpenter, 2011). Data analysis exemplars, such as verbatim quotes from the participants, which reflected the answers to

the proposed research questions, were provided. The researcher provided sufficient contextual information to allow for potential transfer of the study's findings to other areas of inquiry or for the ability to repeat as closely as possible the procedure of this study.

3.12 Personal Aspects and Credibility of the Researcher

In qualitative studies the researcher is the data collection instrument as well as the facilitator of the analysis process. Although there is not a definitive list of questions which establishes researcher credibility it is important for the researcher to include some personal information such as experience, training, prior knowledge of the research topic, and perspective regarding the research topic (Patton, 2002). The above areas regarding credibility of the researcher are presented below.

The initial interest of this study developed out of the researcher's interest in the difficulty experienced when caring for children with life-limiting illnesses in the pediatric ICU and the effects on the healthcare provider. The researcher has over 25 years of experience providing care in this setting to this vulnerable population. The pediatric intensive care unit can be a demanding environment and is where most hospital deaths occur (Jones et al, 2007). Additionally, many pediatric ICU nurses may feel uncomfortable and inadequately prepared to care for children with life-limiting illnesses which may result in death (Waas, 2004). Pediatric ICU nurses often spend a considerable amount of time and energy attempting to identify, meet, and manage the needs of these children and their families during this difficult time. Additionally, pediatric ICU nurses may be challenged by numerous dilemmas of their own thus recognizing that they are not prepared for the challenges of caring for children with these life-threatening or life-limiting illnesses. The researcher's prior experiences in caring for these children has

greatly influenced the researcher to appreciate the need for understanding the human perspective of the pediatric ICU nurse in providing care to these children. To further enhance credibility, the researcher presented avenues to be taken with the intent to minimize the influence of the presence of the researcher in the natural setting and possible bias of data.

Researcher presence.

Researcher presence is described as the reaction of the participants to the presence of the researcher in the natural setting. Participants may react atypically due to the presence of a researcher, thus unduly influencing the data generated. Patton (2002) advocates for a suitable period of time in which the participants and researcher become acquainted with each other. A working relationship currently exists between the researcher and the potential participants of the setting as the researcher is known to the staff as a nursing instructor and per diem nurse in the pediatric ICU. Being known to the pediatric ICU staff may facilitate trust and confidence in the researcher-participant relationship and allow for access into their clinical realm and thoughts. Additionally, the researcher has done previous fieldwork in the unit without difficulty. However, the researcher critically examined how her presence may affect the happenings either in a positive or negative manner within the unit through the use of field notes.

Instrument change.

The researcher is the instrument in qualitative inquires. Lincoln and Guba (1985) put forth that the probability of the study's findings and subsequent interpretations "will be more credible if the researcher can demonstrate prolonged engagement" (p. 301) with participants. Prolonged engagement allows the researcher to discover the context of the

experience and the development of trusting relationships with the participants. However, the researcher must be cognizant of the relationships and involvement developed with the participants. If the involvement with the participants becomes personal for the researcher this may cause a loss of sensitivity regarding the experience and possibly influence the researcher's professional judgment in describing or interpreting the experience (Patton, 2002; Sandelowski, 1986).

Koch (1994) and Cohen et al. (2000) identify that self-awareness through critical reflection is the fundamental work the researcher undertakes to make the inquiry rigorous. This researcher kept a field journal to increase self-awareness. The journal included but was not limited to the following: (1) the content and process of interactions with participants, (2) any reactions that participants displayed during the interview process, (3) did gender differences have an influence on the interview process, (4) how and when did different understandings of the data appear, and (5) in what ways did the researcher challenge her understanding of the data (Cohen et al., 2000).

Bias of researcher.

A criticism of qualitative research is the extent to which the researcher's presuppositions or biases may unduly affect the data collection and data analysis procedure as qualitative studies are often more subjective in nature (Patton, 2002). To minimize bias in this study, the researcher used the strategies of reflexive bracketing and reflexive journaling as previously delineated. According to Cohen et al. (2000) hermeneutic phenomenology views bracketing "not only as the initial step in inquiry but also as the beginning of a process of ongoing critical reflection" (p.88).

Researcher ability.

With the intent to enhance the researcher's ability to conduct this study, numerous articles related to phenomenological philosophy, and the different phenomenological research methods were reviewed and discussed with the researcher's dissertation chair. The researcher worked closely with her dissertation committee throughout the research study and sought advice during the research process and refined the process as necessary.

3.13 Summary

This chapter provided the hermeneutic phenomenological design of which to explore the experiences of pediatric ICU nurses providing palliative care to children with life-threatening or life-limiting illnesses and to obtain an increased understanding of the meaning and interpretation of their experience. Strategies to enhance the quality, rigor and integrity of this research study were suggested and delineated.

CHAPTER FOUR

FINDINGS

4.1 Introduction

Hermeneutic phenomenology as delineated by Cohen et al. (2000) allowed for the discovery of a rich and thick description regarding the essence of pediatric ICU nurses' experiences in providing palliative care to children with life-threatening or life-limiting illnesses. Interviews conducted with 12 participants generated extensive data. The concurrent process of data collection and data analysis yielded tentative interpretations of the data. The interpretations of the data were continuously reviewed, scrutinized, and refined within and between transcripts as data were collected. From the refined data, five major themes were found to depict the experience of providing palliative care to a child with a life-threatening or life-limiting illness. Participant's excerpts from the transcribed interviews are presented to illustrate these themes as well as a description of the study's participants.

4.2 Study Participants

A description of the study's participants was compiled from the Demographic Questionnaire (Appendix A). Twelve pediatric ICU nurses, 9 females and 3 males, meeting the inclusion criteria and purposively selected, participated in the inquiry of the experience in providing palliative care to children with life-threatening or life-limiting illnesses and their families. The researcher recognized the repetition of salient and similar points after interviews with ten participants. Two additional interviews with participants did not reveal any further findings. Saturation of data was achieved with these 12 interviews.

All participants identified themselves as Caucasian. The mean age of participants was 35.4 years with a range of 23 to 49 years. Half of the participants had been practicing in the pediatric ICU less than five years while the remaining participants had been practicing anywhere from six to greater than 20 years in the pediatric ICU. Level of education was split evenly among the participants: 6 participants had earned an associate degree in nursing and 6 participants had earned a bachelor's degree in nursing. Less than half of the participants indicated they had received some type of formal education on death and dying during their nursing career. There was a wide range of experiences with previous loss among the participants, with one participant stating "there have just been too many deaths to count over the years."

Significant variations among the participants including: age, years of nursing experience, years of pediatric nursing experience, formal education on death and dying and previous personal experiences with death was present and provided for a diverse sample related to the study's phenomenon of interest (Table 1).

Table 1

Participants' Demographic Data (N= 12)

Characteristic	Participant n (%)
Race/Ethnicity	
Caucasian	12 (100%)
Gender	
Male	3 (25%)
Female	9 (75%)
Years of nursing experience	
0 – 5 years	5 (41%)
6 – 10 years	3 (25%)
11 – 20 years	2 (17%)
Greater than 20 years	2 (17%)
Years of practicing in the pediatric ICU	
0 – 5 years	6 (50%)
6 – 10 years	3 (25%)
11 – 20 years	1 (8%)
Greater than 20 years	2 (17%)
Highest nursing degree	
Associate degree	6 (50%)
Baccalaureate degree	6 (50%)
Formal education on death and dying	
Yes	5 (41%)
No	7 (59%)

This study utilized a semi-structured interview approach to elicit participants' responses. One broad question and several probes were used during the interviews (Appendix D). The interview process began by asking participants the question "What is it like to care for children diagnosed with a life-threatening or limiting illness and their

families?” Interview probes such as: 1) Go on, 2) Can you please explain that further, 3) Can you give me an example, were used to facilitate further responses, clarification, and uniqueness of the experience. Some participants chose to speak about their experiences with specific children and families while other participants spoke in a more general manner. As the participants shared their stories the essence of the phenomenon of interest as well as an in-depth understanding of the contextual factors associated with the experience was revealed. Pseudonyms were chosen by the researcher to protect the participant’s identity.

4.3 Study Findings

Analysis began with immersion into the data by reading the transcripts several times to identify the essential characteristics of the phenomenon of interest and to gain an initial interpretation of the data for later coding (Cohen et al., 2000). Thirteen essential characteristics were identified from the data (Table 2).

Table 2

Essential Characteristics

Elephant in the room/communication
Nursing staff support and relationships developed between families and nursing staff
Pain/torture
Real hope vs. false hope
Relating to situation on a personal level
Children’s dying is part of the job
The time after/ the final visit
Where in the dying process is the family
Interdisciplinary relationships
Lens of the nurse
Nurse – physician relationship
The children
Stress of job/support for nurses

The iterative process of the hermeneutic circle and reflective awareness was used and provided consideration and understanding of the smallest data statements in terms of the larger context and offered a more in-depth analysis of the data. Following this process, thematic analysis based on the Utrecht school of Phenomenology (Cohen et al. 2000) was conducted and resulted in identification of five major themes with respective sub-themes (Table 3).

Table 3

Major Themes and Sub-themes

Journey to death

- The emotional impact of the dying child
- The emotional impact of the child's death
- Concurrent grieving
- Peaceful ending

A lifelong burden

- Parental burden of care

Challenges delivering care

- Maintaining hope for the family
- Pain
- Unclear communication
- Need to hear the voice of the child
- Remaining respectful of parental wishes

Maintaining self

- Colleague camaraderie and support, personal support

Crossing boundaries

Theme 1: Journey to death.

The interview process began with asking the nurses the broad question “What is it like to care for children diagnosed with a life-threatening or limiting illness and their

families, tell me what that experience has meant for you.” Many of the nurses focused on palliative care during the dying process of children as all of the nurses had voiced, some more forthright than others, that children dying was part of their job. Pensively, the nurses described the multifariousness of the dying process in the pediatric ICU.

The emotional impact of the dying child.

The nurses spoke of this subtheme in the context of providing physical care to the dying child and psychosocial care to the family as the child and family are considered one unit. The physical and psychosocial caring of dying children and their families resulted in a mixture of positive and negative reactions for several of the nurses. Several nurses described caring for children with life-threatening and life-limiting illnesses and their families as remarkably demanding with each situation being unique. Feelings of sadness, frustration, anger, helplessness and defeat were voiced but at the opposite end of the spectrum, feelings of a rewarding day/job and making a positive difference were also expressed.

Two nurses shared different perspectives of the same experience. They recalled the nightshift when they dealt with two critically ill children arresting almost simultaneously. Nurse Becky described how overwhelmed she felt that night. The events of the night occurred so quickly it was difficult for her to comprehend what was happening. She recalled:

We had basically two kids die in one shift you know, and that’s a lot when one child passes and you move on to the next child that their heart stops and you haven’t even had time to, to grasp the death of the first child and you have to move on to stop the second child from dying.

The night continued to be chaotic and Nurse Becky soon realized the parents of the first child to die had left the unit; this was bothersome to her because she did not have a chance to “officially say good-bye” to the parents. She did not feel closure with this family, this left her feeling frustrated.

Nurse Jackie was angry with the situation as evidenced in her voice. She expressed that there was not enough time “to do the things we normally do for families” because of the other critically ill child. She felt as though she had failed this family. Additionally, she struggled with continuing treatment on the second child. The prognosis of the child was very grave but the parents requested everything be done. She had this to say:

It was difficult to continue to code the other child we knew the outcome would not be good, we didn't understand why the numerous codes, she had been down too long and too many times but the family wasn't ready to give up. The docs had talked to her parents but they just wouldn't give up.

Although the perspective of the night was different, the nurses did agree on the need for a debriefing session. They felt this would have allowed them to recap and gain a sense of the night's events. Unfortunately the opportunity did not present itself and they left that morning feeling “exhausted and defeated.” This was a night that was internalized and is still remembered by these nurses.

Nurse Gregg had a combination response to a situation he experienced. He felt as though he destroyed several people's lives one day but yet they (the family) came back and were appreciative of his efforts. He recalled a very difficult conversation with a family regarding the prognosis of their child. The child had suffered a traumatic brain

injury and was not likely to recover but if he did, he would have sustained permanent significant brain damage. The family asked him if he would explain the situation to their other family members. He had this to say:

Can you explain to them [other family members] what you just told us? I explained the whole thing exactly the same to them, so you know there's the tears all very upsetting, then they would leave other family come in, could you explain to them exactly the way you explained it to us, and I did that four or five times that day, that was so hard, that was hard because you're, you're giving devastating news multiple times in one day to multiple people.

This was unequivocally difficult for Nurse Gregg to share as evidenced by his voice. The child died and the family later sent him a thank you note for his kindness and honesty in explaining the graveness of the situation.

Many of the nurses spoke about the impact of caring for children they thought were going to die but survived. Fortunately deaths are infrequent in the PICU and seem to be balanced or even outweighed by the good happenings of the children.

Nurse Charlie spoke of the closeness he has developed with some of the children and their families. It is very meaningful for him when children come back to visit. He stated "it's like they are your own kids" and is what makes his job "all worthwhile" especially when they remember his name. The remembering his name lets him think maybe he made a small difference for the child and family. He is grateful for these good happenings.

Nurse Michelle also spoke about the children who survive and come back to visit. This is very satisfying and allows her to continue to work in the unit. She spoke of one child in particular that wasn't expected to survive but did. She shared the following, "You know she [the patient] is doing really well, and who knew? Her mom is just tickled pink to have her home and thinks it is the greatest thing because she didn't have her home for three years." Nurse Michelle is also grateful for the good situations helping to balance the bad ones.

The emotional impact of the child's death.

The nurses' spoke of how trying and overwhelming it was for them to watch families go through such a terrible situation of actually seeing their child die. Additionally, the nurses spoke of how difficult it was for them as well recognizing this situation could be reversed at any given time. They used terms such as sad, awful, horrific, and mind-boggling to represent their feelings regarding the families' situations. Several nurses stated: "It never gets easier, it always gut wrenching to see the families go through it," "It is difficult to watch," "It's stressful, and with each family you have a different make-up, whether they've accepted it or haven't," "Families are living their lives one minute and the next minute it has changed forever." The nurses noted there had been numerous times when the child was taking their last few breaths that they were "Overcome with emotion," "Had to step out to regain their composure," or "Cried with the families themselves."

Nurse Julie recalled her first experience with death during orientation. She had been taking care of this infant for several days and had established what she believed was a good rapport with the child's mother. This would be a trying situation for her as she had

never been involved in the withdrawal of care, especially that of an infant. She shared the following:

I was working day shift and I remember looking in my closet the night before when I was picking out what outfit I was going to wear saying...now what outfit do you wear when you are going to kill a baby? Honestly that was my thought! What do you wear to kill a baby?

She learned a lot from that first experience with death. She tries to be as prepared as possible with the intent “of making it as easy as possible” for everyone involved. Since her first experience with death, she admits difficulty with putting children in the shroud and zipping it closed. She believes this stems from her first death experience and the relationship she had developed with the infant’s mother. The mother had a great deal of trust in Nurse Julie and when the mother handed the infant to her for the final time, the mother said to Nurse Julie “I know you will take good care of her and thank you for that.” Nurse Julie was very emotional as she described this experience.

Nurse Clare recalls a very sensitive death experience. A baby was undergoing brain death criteria and this was something she had not experienced. She recalls feeling “awful” about gaining an educational opportunity for herself when these criteria would determine life or brain death of this child. She called to mind:

I went to the first brain death criteria, I went to this kid’s parents afterwards and I said I’m so sorry I didn’t mean to just like come in and [child’s mother’s name] said to me we were so glad you were here, you were the only familiar face in the room. I will never forget when Dr. [physician’s name] said time of death after

brain death criteria two; he had failed and said time of death, whatever time it was. The kid's mom looked at me and said [nurse's name] what did she say? The following statement was most memorable for Nurse Clare. The parents had been educated that if the child failed the criteria twice he would be "technically" dead. The parents were unable to process this and as Nurse Clare noted "because to them death was not death with brain death, it's with the last of his heartbeat." Nurse Clare had to tell them that their child was dead even though his heart had not stopped beating. As she spoke of this she became very emotional and said it was difficult to keep her composure when she talked to his parents.

Collective among the nurses was that dealing with death, whether an acute or chronic situation is difficult. However, many nurses found one situation more difficult for them than the other. Several nurses spoke of the intensity and pace of an unfavorable outcome for the child with an acute illness/injury was obviously overwhelming not only for the families but for them as well. The families are living their life one minute and the next minute are in a state of chaos due to circumstances beyond their control. Several nurses mentioned the tragic events of children with an acute illness/injury often happen so quickly they do not have a chance to grasp the situation at hand. They are left wondering what just happened.

Nurse Charlie spoke of how hard it was some days in the PICU to comprehend certain situations. He believes it is more difficult when a child dies suddenly because there is no time for anyone to prepare. He spoke of a 16 year old young man admitted with what appeared as a minor accident, had been well prior to admission, but died after four days. Nurse Charlie had this to say:

So in other words you got an otherwise healthy 16 year old boy who has an accident and is all of a sudden here and he just spirals down and you can't really help him for whatever reason. You can't figure out what the underlying condition is and before you know it he is no longer with us. He ate with us and was telling us he had no pain and within four days he was dead, he had fungus in his cerebrospinal fluid, but we had found out of course after he had passed.

This situation was upsetting for him. He did not understand how everything had fallen apart so quickly with this young man. The young man had been responding to antibiotics and then plummeted. Nurse Charlie felt sad, helpless, and defeated after caring for this young man.

Nurse Jackie had a similar experience. After working aggressively on a child and realizing nothing was working, she felt a sense of loss. She shared, "I mean you want to do everything you can for them, you pour all of your energy into this kid, all your knowledge and skill is not helping, and as much as you want to help, it just is not happening." Knowing nothing would help was hard for her to process. She felt as though she had caused the child undue pain "torturing this kid" for her twelve hours of work. Nurse Jackie realizes this happens and that children die but she does not like it.

Nurse Julie also felt that the death of a child with an acute illness or injury was more difficult, very tragic in nature and she is "bothered by them more." She discussed how families are obviously still in shock from the entire event. The family has had this healthy child all of these years. They have created lasting memories and planned for their child's future. In a matter of seconds that is taken away from them and they are told their child is going die. How would she react? She tries to put herself in that predicament

thinking what she would do if she received “that” phone call. She wonders how one adjusts to knowing their child is dead. She remembers a family who lost both their sons from one accident. Talking about this experience was difficult for her as evidenced by her voice. She shared the following:

We [PICU] had one not too long ago in where there were both sons that these people lost in the car accident, their one son died on the scene and their other son died here a week later. I mean my God how do you live with that? And those were the only two children they had...so that one really bothered me. I just could not even imagine losing both your children in a week’s time frame from the same accident...I mean it just cannot get any worse than that to me.

This was hard for her to watch the parents go through such a horrific ordeal. Their life as they knew it was forever changed because of a freak accident. Nurse Julie tries not to let these situations bring her down but sometimes it is “too much” and it does.

Some nurses spoke of their thoughts surrounding the death of a chronically ill child. The parents have been around the hospital environment for many years. Thus they are comfortable with the surroundings and happenings of the hospital because of numerous admissions. The parents are familiar with the nursing staff and have developed relationships with them over the years. For the nurses, these relationships developed with the families were foremost in their accounts.

For Nurse Gregg, he has a greater difficulty with the death of a chronic child because of the bond he has formed with the child and family. He feels the attachment is typically stronger because of knowing the child and family for many years. This makes the situation more trying for him. He described the following, “You do know them well,

so well and you've, you've had lots of laughing time with them over the years, you've had lots of set time with them over the years..." Each time the child is hospitalized, he wonders if this will be the time he says his final good-bye.

The emotional impact of children dying was personal for many of the nurses as well. Many of the nurses indicated that the active dying process of a child made them stop and think that this could happen to their child or family member at any given time. The nurses recognized the need to appreciate the "goodness" of every day. The impact became more pronounced if the dying child reminded the nurse of their own child in some way.

Nurse Charlie spoke of how these situations [dying children] put things "into perspective" for him. He described a "tough situation" for him and how terrible he felt and why: "I don't remember what he [the child] died from but they [the family] are all in the room weeping of course and there's a bunch of us [nursing staff] and docs trying to console the family, their child was 3 and my son was 3 so that hit home!" He shared he takes nothing for granted and appreciates everyday with his children because of the situations seen in the PICU. He considers himself "very lucky."

Nurse Michelle recalled a situation that is "etched in her mind forever." The child she was caring for was the same age as her son, had the same hair color, and his name started with the same letter as her son's. This situation also occurred around a holiday thus an annual reminder she wanted to forget but cannot. She shared vivid memories of the situation as if it had happened yesterday. She recalled:

I did not see it coming, I knew he was sick but...the next thing I knew he wasn't breathing! We [physicians and nurses] did everything we could but the damage

had already been done. We worked all night but nothing helped. He died early Thanksgiving morning.

One could hear the distress in her voice as she spoke of the night. This situation was her constant reminder of realizing how quickly things can be turned upside down and how lucky she was to have healthy children.

Very few people work on the hospital unit where they have had a family member die. Nurse Jackie had this experience. She shared that “having been on the other side” was a positive experience for her. She believes this experience has given her a sense of understanding the process parents go through when their child dies. She lost her four year old foster brother, this was her first death. As a nurse she wanted to take care of him but as his sister she knew it was time to let go. This was a dilemma for her. She did not want her brother to die but did not want to be selfish and keep him alive when he was suffering. There have been times she has shared her story with families in turmoil hoping it brings them solace.

Nurse Melissa recalled a challenging and frustrating experience in caring for a chronically ill child. There were no new medical options to offer, but the parents insisted on continuing treatment for their child. However, they did not spend much time at the hospital. This was very difficult for Nurse Melissa to share as she became emotional recalling the experience. She felt as though she was causing the child undue pain and that the humane thing at this point should have been to make him comfortable to die. She shared: “Do everything, do everything, do everything, do everything but, they [the parents] were there for maybe a half an hour a day not witnessing what we were doing to their child.” When asked to express how that made her feel, she stated “Horrible, sad,

helpless.” This was a quandary for Nurse Melissa because as a parent she was not sure she would be able to let go, but because of her experiences as a nurse she felt that was the right thing for this child.

Nurse Becky remembered an experience where the child had been declared brain dead and the parents were asked to donate their child’s organs. This situation was very personal for her as this young man was the same age as her son who had recently passed his driver’s test. One could hear the emotion in her voice as she shared the following:

Had a 16 year old that was in a car wreck, he was brain dead and we ended up withdrawing support on him. He ended up being an organ donor and those are kind of hard times when you have a child yourself that’s close in age to a kid that dies and is in a car accident because it brings reality home that, that could be you at any given moment where your child goes out and makes a stupid mistake.

These situations are very eye opening for her as she recognizes it could be her walking in those shoes at any time. To know this child was healthy, not sick in any way and is now donating his organs because of an unfortunate accident is difficult for her to understand and accept.

A few of the nurses made reference to “regardless of the clinical things [resuscitative efforts, procedures] going on in the room” do not forget the family behind the child. Nurse Clare shared an experience of caring for an acutely ill child where she felt that had not been accomplished. Several nurses and doctors were in the room with her working frantically to stabilize this young person. In the back of her mind she was thinking that somehow amid the chaos she needed to find a way to get the family into see their child in the event he died. She recalled:

I barely saw their [the parents] faces and all you could see on their faces was the look of, oh my God, why are all these people around my child? I remember his mom was crying and his dad was still trying to put up a good front at that time and still be strong. All they saw of him was a tuft of his hair?

This was very personal for her as she also had a family member die in the PICU as well. She remembered the nurses were not supportive to her or her family during this difficult time for her. Nurse Clare did not want to make the same mistake as she remembered how she felt in that situation. It was longer than she wanted but Nurse Clare was finally able to get the parents into the room and update them on their son's condition.

Concurrent grieving.

Many of the nurses stated the need of recognizing where the family is in the grieving process. This affords the nurses an opportunity to gain a perspective to guide them in meeting the families potential needs during this difficult time. The nurses voiced the importance of exercising patience with the families, being supportive, and recognizing denial is a powerful emotion as everyone is trying to make sense out of a senseless situation. Additionally, the nurses spoke to experiencing their own grief with the death of a child.

Nurse Jackie is among one of several nurses who stated the importance of being familiar with stages of grief and supporting the families as they proceed through these stages. She recognizes that she grieves as well. However, she has noticed she is typically at a different stage than the family. She has learned to exercise patience in allowing the family their needed time to accept the situation. She shared the following:

I found myself on one kid I realized I was getting upset with the family for not being as far along in the grieving process as I was. I was to the acceptance, like you know this kid has been through awfulness, and okay, we're there and someone needs to let him go, and they were still back in denying that this was a problem. They [the family] thought he was going to be all better. I was like come on, it kind of dawned on me like you're ahead of them in the process let them, give them, time to catch up!

This was a significant realization for Nurse Jackie. She believes that it has helped her grow professionally and that she can better care for these children and families during this difficult time.

Nurse Michelle had similar thoughts on the multiple factors involved with the grieving process. She believes that during this difficult time it is essential for nursing to be very supportive and caring to the families. They are struggling to make sense of a senseless situation. She concurs with Nurse Jackie that it is important to recognize where the family is in the grieving process. She also believes there are additional factors that influence the process. She stated:

I think sometimes depending on how the families are, what kind of rapport they've had with the staff and depending on who's involved. You know depending on how long they've had to come to a point where they may realize this child may not survive versus it being something relatively quick. Who knows what their coping mechanisms and all that you know, what other stressors they may have at home?

Nurse Michelle also struggles with the concept of children dying. It is difficult for her not to become attached to the child and family even if it is only a short period of time.

Peaceful ending.

The nurses noted whether a short or long journey to the death of a child, it was a challenging time for everyone involved. They reflected on the need to try and make some type of a positive outcome for the family from a negative situation (death).

Nurse Michelle believes it is very important to make that last “time” with the child as personal as possible for the families. She wants to allow families “their time” to make that last visit as memorable and pleasant as achievable. Accommodating all of the family’s needs at this time is a high priority for Nurse Michelle. She shared the following:

You know let all of their gazillion family members in, pray, do whatever is needed. If we can get the families involved like bathing the child or something like that or if there is some ritualistic kind of something they would do, read a book to the child or something that they would have done at home and if it’s possible, hold the child or depending on what the circumstance are get in bed.

And some families don’t want to and that’s ok too.

Nurse Michelle also spoke of giving the parents a clay handprint and a memory box with special items to remember their child. She has found this to be well received by families and hopes it provides them with some sense of comfort.

Appearances of the child after death were important to and for the nurses. The nurses did not want the parent’s last memories of their child to be unpleasant. Instead the nurses wanted to create a degree of “any kind of niceness” they could to lessen the

remembrance of the sights, the sounds, or smells of the experience and to make that last visit bearable for the families. Several nurses commented.

Nurse Maggie tries to make this situation the best it can be for the families. Even the littlest actions seem to help families at this time. She noted “If it’s like an infant nothing’s better than a little bit of lotion and powder and you know and I mean it doesn’t fix everything but it’s they [the parents] should remember the snugly good things about the baby not this yucky stuff.”

Nurse Norah makes every attempt to have the child as “clean” as possible for the parents. She believes that a clean bed and stuffed animals helps families but most important for her is a clean appearance of the child. She stated, “Just making sure that there wasn’t like blood all over the blankets, or like that his mouth was clean, that his face was clean, that he looked I guess presentable or at least the most like himself that he could.” Nurse Norah will also do her best to facilitate a parental request to hold their child one last time or lay in the bed if possible.

Nurse Elisa had been consistently caring for a young lady well-known to the unit. This was the admission that would not end in discharge to home. Everyone knew the child was dying. Nurse Elisa had “the feeling” that something was going to happen that night. She decided to bath the young lady earlier than planned. She finished her care around midnight and had the young lady “looking beautiful in bed.” Shortly thereafter, the young lady began agonal breathing. Nurse Elisa knew this was the beginning of the end and called the young lady’s parents to come. She was glad she had reacted to the feelings from earlier that night and had the young lady “looking as though she were sleeping in her bed at home” for the arrival of her parents. She believed it was consoling

for them to see her this way. Being able to provide simple comfort measures for the dying child and their families were important to these nurses, it gave them a sense of meaning during a difficult time.

The nurses also spoke to the need for effective pain as well as symptom management at the end-of- life. They believed this to be a significant source of distress for the parents. The nurses voiced the need to facilitate as comfortable an experience for the child and family at this time. They wanted to make the remainder of the dying process as “easy” as possible for the parents and perhaps themselves. Whether the parents had chosen to withdraw support or stop treatment the nurses felt this was probably one of the hardest decisions they would make in their lifetime. Many of the nurses voiced they were pretty comfortable giving pain medications during the dying process as they believed they were helping the child and parents get through this time.

For Nurse Gregg it is essential that the families understand their child will be very comfortable and “not struggle.” He shared a personal experience of his father dying peacefully and comfortably. This was very important to him and his family. He wants to make the dying process for the child and their families similar to what he experienced if possible. He has learned through his many years of experience that administering medication at the end-of-life “is a huge deal for parents.” Having the child appear comfortable and relaxed is the memory he tries to create for parents as that is the memory he holds of his father’s death. He recalled a situation early in his career regarding a 15 year old adolescent on whom they were withdrawing support. He remembered the following:

We withdrew support and the kid gasped, gasped for like an hour or two, you know I was a newer nurse and didn't know any better, but to say "we need more drugs" it was tough to watch I can't imagine being the mom that laid in bed with him.

He has gained a lot of insight from his many years of practice and is now quite content giving perhaps a larger dose than would be on a normal everyday basis.

The nurses did not want to see the children struggle in any manner; they wanted the children to look as if they were sleeping peacefully. This concept was very important to Nurse Julie. She shared:

"I want to know that this baby is going to lay there with their eyes closed peacefully and just go to sleep. So when I give that Morphine or when I am preparing that Morphine I feel very good about that.

Nurse Julie believed this was the best way she could help the family after they had made such a difficult decision. Nurse Jackie shared this sentiment as well because of a personal loss she had experienced. She voiced, "I think they've all gone comfortably, I've never seen them struggle, never." She too believes in a peaceful death and feels she has accomplished that in her clinical practice. Nurse Charlie is also a believer of pain medication to "ease the process and comfort the child." Seeing children suffer is something that "hurts too much and is upsetting for him."

Many of the nurses spoke regarding how appreciative families often are after the death of their child. This was perplexing for the nurses. Nurse Becky, through her many years of experience, shared that she could not remember a death of a child in where she was not "rewarded" by the family. She often thought and was expecting that the family

would be angry but instead the family showed an “immeasurable amount of gratitude.” She believes the family is grateful not to experience this process by themselves. She also described the importance of attending the children’s funerals to achieve closure. She again mentioned that families are grateful the nurses come and “it showed them [the family] that their child was important to me.” Nurse Becky carries with her the memory of the first funeral she attended. This is still emotional for her present day as was evidenced by her voice. She shared:

I was very young and an inexperienced nurse. I was “summoned” by the patient, a 13 year old boy dying of cancer, I walked into his room and I said what’s up [patient’s name] and he looked at me and he said I just wanted to know if you would come to my funeral. I looked at him and sure as long as I have directions, because I didn’t know what to say to him. I wasn’t expecting that question it was like out of the blue and then driving home I remember crying because I thought you know like he should be inviting people to his birthday parties and here he’s inviting people to his funeral.

It was very important for Nurse Becky to fulfill her promise to this young man. She attended his funeral and was able to spend some time with his mother. This was very rewarding and comforting for her and she believed for his mother as well.

Nurse Maggie shared her personal opinion regarding what constitutes a “good death” for her. She stated:

I feel that they should not be in pain; I feel that they should be comfortable. I feel that it should be peaceful, not traumatic, not a traumatic death if at all possible if we can control that I think that it’s good for the parents it’s obviously good for the

patient just for it to be as peaceful as we possibly can make a horrible, horrible situation.

Providing a peaceful ending is the general consensus among the current study's nurses.

A lifelong burden.

This theme was discussed primarily in relation to children who had suffered an acute injury and were left devastated from the injury or those who suffered from a progressive chronic illness and would require extensive lifelong care.

Parental burden of care.

The sub-theme of parental burden of care evolved as this was viewed by many nurses as emotionally exhausting for the families, but particularly the mothers. Additionally the nurses felt a tragedy of this degree did not affect just one but could have consequences for the family. The nurses sensed many of the parents had not been able to reach acceptance and reality concerning the loss of their child. The parents had learned to cope and provide a sense of normalcy the best way possible. The nurses felt it "wasn't their place" to initiate a discussion with the families regarding the option of stopping treatment. Instead they continued to support the families in their current situations. Several nurse recounted their experiences.

Nurse Clare discussed a very trying situation in which she was caring for a young child who had been struck by lightning getting off the school bus and had suffered a horrific anoxic injury. She had become very close with the family and found it challenging to care for him as she knew this child's quality of life would never be the same. Yet, his parents had not reached that realization. She recalled the following:

I mean he has truly has lost the whole essence of himself, his family has lost the essence of this child and again and maybe this it's just that I have over thought this time and time again, but I think of his sisters and how their life must have changed and now how his parents' lives have changed, because we tried every effort and even, you know when we put the facts out there to the parents at times...

She stated she carries this experience with her daily as she wonders if an injustice was done by saving him because of the severity of his injury and subsequent quality of life. It was painful for her to see him again when he visited the unit in his wheelchair and was not responsive to any type of stimuli. However, his family seemed happy to have him the way he was and, therefore, she thought maybe that was a gift itself.

Nurse Alan talked about the taxing decisions he has seen parents whose child had survived a devastating injury face. He couldn't imagine how difficult it was for them to decide if they wanted to trach their child because they needed a ventilator to breath or have surgery to place a feeding tube to eat through possibly for the rest of their life? "Would the child smile again, talk again, respond in any way?" "Did the parents really understand what life would be like for them and their other children from here on out, were the doctors as upfront as they could be? To think that this child may do nothing more than lie in the bed, the body was there but nothing else." The families had to wait and see what progress the child made. As a parent, this was difficult for Nurse Alan to watch families go through.

Nurse Charlie spoke about a young girl who he had cared for many times. She was suffering from an intractable seizure disorder and the therapies were no longer

working. She was placed in a chemically induced coma each hospitalization and each time she was in the coma longer. When she finally came out of the coma, a piece of her “had been lost.” When asked about her illness progression, he recalled:

It was a downward spiral, no matter what we did, we changed her drug regimen, we did different therapies, you felt helpless, nothing seemed to help, you felt terrible, you almost had to turn your back, it was terrible, you couldn't do anything and her mother just sat at the bedside.

Nurse Charlie also recalled how hard it was to watch the patient's mom just sit there and stare at her daughter. Additionally, her family lived over two hours away. Her mom was there alone because her stepdad was at home with her two younger sisters. When her sisters came to visit they could not interact with the patient because she was in the coma. This situation was very difficult for Nurse Charlie to share.

Many of the nurses expressed sympathy regarding the difficulties families faced when caring for these children. They watched families struggle with trying to maintain a sense of normalcy. Nurse Alan shared the following, “And once you decide that [continued treatments/procedures] it's an extra stress on you [the parent], your family, siblings, and the spouse. That's no life for the family, it's no life for the child, and it's no life for the child's sisters or brothers.” Nurse Gregg had similar thoughts. He recalled, “And even though you discuss and tell the family not to neglect the healthy child her birthday or his baseball game or what not, inevitably they do.” The nurses hoped the families would achieve some type of balance in their family life.

Challenges delivering care.

The nurses articulated that at times circumstances arose with the children, families and physicians causing challenges delivering care. Additionally, the nurses spoke about the development of personal quandaries related to these circumstances which made it more difficult for them to deliver optimal care.

Maintaining hope for the family.

Both the giving and unintentional taking of hope occurs frequently in the context of the pediatric ICU. Many of the nurses believed that hope for survival continues for families up until moments before death. The nurses recognized how important it was to instill a sense of hope through their caring for the families despite disease progression and failure of medical therapies. However, the nurses noted certain situations made it extremely difficult to espouse a sense of hope for the parents.

Nurse Michelle had been caring for an adolescent who had suffered a traumatic brain injury. She recalled the difficulty she had on containing her opinions on “what would she do?” in this situation when asked by the parents as she did not want to take away their hope or impose her personal views on the situation. She stated:

They didn't want to and I believe it wasn't even an option I think he was brain dead, they did not want to give up that last ray of hope and you can't take it away from them, but it comes to a point where you have to realize this, this isn't going to get better.

This situation presented a dilemma for Nurse Michelle. Because of her many years of experience she has seen the outcome of these situations. They are not favorable.

However, even with that knowledge, it is difficult for her to share her personal views with parents. She feels “guilty” taking away their hope.

Nurse Melissa has a similar problem as Nurse Michelle. She too struggles between having “seen” what she has during her career in the pediatric ICU and not wanting to give up hope. She recalled an experience in which the situation could not be reversed and the outcome would not be positive. She stated:

We provided CPR for thirty minutes and there was nothing else that could be done... yet the family was there cheering her on. Seeing what I see and dealing with that it's hard because I have a hard time having hope in those situations. These situations are extremely difficult for Nurse Melissa as she knows there will be a negative outcome but yet “you still do” for the parents sake.

Nurse Jackie expressed that at times she believes we give a sense of false hope, as health care professionals do not want to or like to admit defeat. She believes that because the nurses are at the bedside they see how the families understand the situation. This can be trying. She had this to say:

The family you know latch on to that 3% chance that their kids going to make it, and so even though you've told them thirty minutes of how this is not going to happen those last three words that you say, that's what they hear, because that's what they want to hear, and rightfully so and so we say the 3% chance of living, but we don't say the 97% chance of dying. I think that lends itself, to you know they have a number to hold on to where if we gave them a 97% chance of dying they may not think that there is a 3% chance of living. Just the psychological way

that a number would work in somebody's head, and so again they [parents] hold on to that.

Even though Nurse Jackie is aware of the poor outcome, she has difficulty dashing that 3% of hope the parents still have.

Nurse Charlie shared his views on remaining optimistic and holding onto hope when the odds are against someone and believes it cannot and should not be assumed that the child will die. He stated "If you don't have hope, then what is there?" He believes there is always a chance, however small, because children are so resilient. He would support the families throughout the illness and dying process and when the point had been reached that there aren't any options remaining, he would concede and "let the child go to a better place."

Once again because of the significant amount of time the nurses spend with the child and families, the families come to rely on and look to the nurses for hope, guidance, and support during this arduous time.

Pain.

Many nurses of the current study spoke of causing pain as a challenge to the delivery of care. It seemed several of the study's nurses believed that due to parental requests, advanced treatments and sometimes unwillingness to stop those treatments children suffered unnecessary pain. The nurses expressed they felt the children were often put through what seemed as pointless procedures and continued treatments which did not change the child's outcome but instead caused further pain or prolonged the inevitable (death).

Nurse Michelle shared one of her experiences with pain management at the end-of-life. It was a disturbing situation as she watched what the child and family went through. She was livid with the physician for creating the situation. Additionally she felt helpless and frustrated as there was nothing she could do to mitigate the child's or parents distress. Her tone was that of anger as she described the experience. She had this to say:

One particular case taking out of an IV, the only IV access in a small infant and withdrawing support. Thinking the child was going to pass quickly, did not pass quickly. The child was struggling, struggling and the attending was the one that pushed to have the IV removed. I believe he may have taken it out himself. That mother and father said they would have rather had a gun and shot the child than have her agonize; the child lived for an extended period of time. I couldn't give anything else; it felt like torture because the baby was a small. I felt horrible I was sick, absolutely sick and I told that attending afterwards, after I got over being angry, I said never again!

Thankfully Nurse Michelle has never experienced this type of situation again and for that she is grateful. She noted this was the worst experience of her career.

Nurse Julie spoke about how she felt that serious chronically ill children were in a lot of pain and discomfort during their lifetime. She notes the child's quality of life, in her opinion, is typically not "fantastic" and that the child has been limited in life experiences. She shared her thoughts:

I almost feel a relief for the child most of the time, maybe because their quality of life has never been fantastic to begin with mostly what they've experienced in

their life is going from bed to chair, chair to bed, never really showing a lot of emotion but feeling pain throughout all that time.”

She is sad for the family who has devoted so much time and loves their child dearly; she cannot imagine what they are going through. However, Nurse Julie does feel a bit of happiness for the child as she believes their suffering is “going to end soon.”

Nurse Melissa recalled her experience in caring for a young infant that had been transferred back to the medical center after receiving needed treatment at another facility. His course was complicated and the experts at the transferring hospital said his condition carried 100% mortality rate. His parents refused to stop treatment. She stated: “Providing care was painful to him, he would grimace and cry and we continued to care for him because the only other option was to just let him go but the parents weren’t willing to give up.” She seemed to be having a difficult time caring for this child as multitudes of tests being were being done at the time and these were causing him pain. She felt as though she was “torturing” him and this made it hard to continue to care for him knowing she was physically hurting him.

Unclear communication.

The nurses described two types of communication exchanges occurring in the pediatric ICU. These exchanges of communication happened between the families and physicians, as well as nurses and families with the latter the more remarkable of the exchanges. Most of the nurses spoke to the overall communication exchange between nurses and physicians as respectable. No one indicated any difficulties in the ability to approach and speak with the attending physicians regarding their patient’s plan of care. However, when the nurses were asked “Tell me more about the communication between

the families and the attendings,” numerous responses were noteworthy. Most nurses were in agreement that some of the physicians were better than others at presenting the delicate matters of care with families. Again certain physicians were easier for families to understand while others “spoke above” the family’s level of understanding.

Some of the nurses also noted that physicians would “sugar coat” or “paint a pretty picture” of the situation and were “not completely honest and upfront on the route the patient was following or their true condition” when speaking with families. This often led to difficulties for the nurses because they were left to deal with the misperceptions that arose from these physician communication exchanges.

Some comments included: “I think just as somebody looking in on the situation, I think that sometimes of course the families like the sugar coaters better. So I think it impacts their rapport with the attendings and of course we banter at it, around, behind their [the physicians] backs about why they didn’t say the truth, why they aren’t upfront, just tell them [the families] that”, “I was really disheartened in the palliative care meeting, I was mortified when I was in there how everyone [physicians] beat around the bush you’d think they [physicians] were talking about anything other than the patient.” Many of the nurses referred to the “elephant” being in the room; let us talk about everything except what we really should talk about. They believed the families deserved honest communication from the physicians. The nurses did not feel that occurred routinely. Additionally, they voiced being uncomfortable challenging the physicians on this aspect of care.

The nurses believed it was essential for them to be part of the physician and family conversation. This allowed the nurses the ability to obtain accurate information to

assist the parents in the decision making process, noting that everyone was then “on the same page.” Nurse Maggie believes that to provide quality care she should be aware of what is being discussed with the family. She had this to say:

I think nurses have a little bit more intimate relationship with the families than the physicians do. I want to make sure I’m in on any conversations that go between the parents and the physician so that I’m in the know of what’s occurring and that I can help better explain or, or facilitate that communication between the families and the physicians and be a kind go between not a middle man, but a go between to make sure that those conversations are accurate or if they have any questions.

There have been times when Nurse Maggie has had to “step in” and request the physician try again with another conversation. She noted occasionally it takes more than one conversation before the families can grasp the seriousness of the situation.

Nurse Alan described his thoughts on the numerous factors that can come into play during communication with families. One factor particularly challenging is the number of physicians involved in the care of the critically ill child. Parents are receiving information from many physicians simultaneously each with their own agenda and it becomes difficult for the families to process what is being said. He shared this:

Physicians typically talk in more medical jargon than the families understand. When the doctors are running through these medical terms in several situations you have different doctors calling the same thing different things because it depends on their specialty which confuses the family. You have different doctors from different shifts come in and give different outlooks on the same object so the

family thinks they are going to fully recover, partially recover, or not recover.

Sometimes it is the physician's accent, sometimes it's their train of thought, and most times it is just hard to figure out!

He believes this makes it very challenging for families to obtain a clear picture and grasp the seriousness of the situation. There have been times when he has had to ask other nurses what the answer was after the physician had finished speaking!

Need to hear the voice of the child.

Many of the nurses had a strong belief that the child "should have a say" in the decision of their care. While the nurses appreciated the different reasoning abilities of the child, when appropriate, they believed the child's voice "should be heard" and it was important for all to keep in mind the child's best interest. When presented with the question of "Whose wishes to follow, child or parent?" the majority of the nurses agreed that it should be the child's, especially with the older adolescents. The nurses stated they felt the children had a strong awareness into their situations and had accepted their fate often before others.

Nurse Clare recalled shared how she has considerable respect for these children in the strength and courage they display when facing death. She spoke of their keen insight about the situation. She shared the following:

I think kids that know they are dying have one of the best perspectives on life, not only theirs, but everyone else's. I love learning from those kids because I truly think that they have it figured out. They really see, they know who is going to handle it, they know who's not going to handle it, they have already accepted what is happening, when know no one else has. They tell it like it is.

She finds that these children are at peace with everything.

Difficulties arose for the nurses when the parental and child wishes were conflicting. The nurses expressed they tried to assist the child and the family to come together, see each other's point of view, and subsequently reach a mutual consensus, but that does not always happen. Nurse Gregg shared one of his experiences, noting that it is hard to "be in the middle" of these situations as you [the nurse] can see both perspectives but he advocates for the child. He wishes that parents would listen more to their children. He recalled the following:

I can remember specifically a hematology oncology kid that we had who was like 17 and he did not want to continue. He did not want to keep having chemo, did not want to be intubated, he was tired and he wanted a rest, he wanted peace. His parents, "Nope, sorry we're going to do everything we can, do everything we can" as I recall. But he was one where after he turned 18 he stopped and he passed away shortly thereafter, because he knew what he wanted.

This was a difficult situation for Nurse Gregg. He cannot imagine being a parent and agreeing to let your child die. However, if the child is insisting he believes, when appropriate, the child's wishes should be followed.

Nurse Michelle recalls an experience in where she was caring for a 16 year old young lady who had suffered a traumatic brain injury as the result of a motor vehicle accident. The young lady had not met brain death criteria but had suffered a horrific anoxic injury and was left devastated. The mother and daughter had "discussed this type of situation" and the mother knew the daughter's wishes. However, it was very trying for the mother to make the decision to withdrawal support, but due to the nursing staff

support, the mother was able to follow through with her daughter's wishes. This caused a great deal of emotion for Nurse Michelle as evidenced by her voice. Nurse Michelle shared the following:

I think she looked to a lot of the staff here she became somewhat close with us, you know some sort of level of compassion from us. Her mom asked if this happens a lot to other people, was she being a bad mom. You know I wish I was as strong as her [the mom] because if, if I had that [the situation] and would be able to be strong and follow through with her [the daughter's] wishes not just be selfish and want her body around. And she [mom] ended up withdrawing and she thanked us, she came back and thanked all of us for being very supportive with her.

This was a situation Nurse Michelle said she would remember for quite some time. The strength and courage this mother showed during probably the darkest hours of her life was amazing to her. She hoped that if ever faced with this situation she too could follow her daughter's wishes.

Remaining respectful of parental wishes.

Whether a child with an acute or chronic illness/injury was dying, and treatment was continuing regardless, attempting to remain respectful of parental wishes was trying for the nurses. The nurses recognized no one is typically prepared for death let alone a child's death. The nurses stated they are parents as well and wouldn't give up on their child, but there are times when the end has been reached.

Nurse Maggie, being a mother too, appreciates how difficult it could be for parents when their child is dying. She would want to be in control of her child's destiny and not having that control would be challenging for her. She had this to share:

I try to put myself in their [parents] shoes, I'm a mother so it does give me, a multi perspective caring for this patient, because she is my patient but also, if I were this patient's mother I would want to be in control of the situation so I think that, that is the most difficult part for me. I know how desperately a parent can be hanging on to that, last thread of this is my child.

Recognizing the difficulty she would have if faced with this situation, she tries her best to respect the parent's wishes.

Nurse Michelle said she typically does not share her personal views or ideas of what should or shouldn't be done with parents. She does not want to influence their decisions. She is happy to be a "sounding board" for the family. But it then becomes difficult for her when families "straight out point blank" ask her what she would do if it were her child. She strives to give the family the best answer she can without being disrespectful to their wishes.

Nurse Charlie shared a very sensitive situation. He spoke of a young lady who suffered from an intractable seizure disorder. He had cared for her numerous times over the years. The young lady was hospitalized repeatedly throughout the years. The medications were no longer working and she continued to seize even when placed in a Pentobarbital coma. It was excruciating for him to watch this young lady deteriorate over the years. As he recalled the experience, one could hear the emotion in his voice. He said:

Her mother of course wanted everything done each time, which brings up a whole other issue. When a child has a debilitating disease or suffers from a condition like that, I do believe that it is better sometimes to let the child go but to see the mother so upset it really affected me... I don't think children should die before their parents, I don't think that is the way God intended.

Being a parent himself, he understood the mother's need to continue with treatment but felt the young lady had suffered in the long run.

The nurses voiced that they are often the first to recognize the inevitability that death is imminent because they are at the bedside with the child, they see the subtle changes. However, the families may not be accepting of this. Regardless, the nurses' focus switches to making these last moments, hours or days as comfortable as possible for all involved.

Nurse Maggie wondered "why we do what we do" at times. She realized that if it were her child, she would want everything done too. It is hard to determine when to say "enough." It never feels right even when it is. She shared the following:

I think that we do things for a lot of different reasons and I think that one of the main reasons it might appear as if it seems like we are prolonging the inevitable is because maybe there is therapy out there that is worth trying but, also to get everybody involved, because we have so much vested emotionally in these patients and to abruptly stop treatment or therapy, I think would take a toll on everybody especially the parents.

Nurse Maggie is a firm believer that children are resilient and should be given every opportunity. She thinks providing the available and appropriate opportunities makes a better all-around situation for everyone involved.

Nurse Alan shared a story about a young infant that had outlived her projected life span. He had become very attached to this baby and her family. The baby had spent most of her life in the hospital because of her genetic disease process. She had recently taken a turn for the worst. Based on the progression of her disease, there was little to offer the baby. Nurse Alan shared the following:

We cannot fix her; we want you [mom and dad] to have your time with her. Right now she is sedated and intubated, we could sustain her this way for quite a long time if we continued on the plan, her mom and dad were I understand we don't want to put her through any extra pain, we want her to get better, but she isn't going to get better. They [mom and dad] just wanted what was best for her; they had to settle out for themselves. Luckily that little girl, mom and dad were going to make a decision that morning but she died at 7am in dad's arms...so that was good

Nurse Alan was glad the family did not have to make that difficult decision; it was made for them by their daughter.

Nurse Melissa was involved in the care of a young infant who appeared to be in a constant state of pain. She noted how frustrating and helpless she felt in this situation. She attempted to speak with the physician regarding care and her suggestions were not well received. Additionally the parents were not willing to stop treatment further

complicating the situation. She spoke with irritation in her voice as she shared the following:

The doctors that are providing the care, it's frustrating because we [nursing] feel one way and the family feels the other. I had with a patient that I felt like we were just torturing him, providing care that was painful to him. He would grimace and cry and we continued to provide the care for him because the only other option was to just let him go. I had mentioned that to one of our doctors and his comment back to me was what do you want me to do pull the trach and put the pillow on his head?

Nurse Melissa felt the medical team did not have the answers to solve his problems.

Attempts were made to fix his problems with more medications and these were unsuccessful as well. She "resented" the doctors and his parents for putting him through this unnecessary pain.

Nurse Elisa described an experience regarding a young two year old child in which the mother dictated the child's care. She did not know how or why this had happened it was just the way it was making it a very difficult situation because needed care at times could not be provided. The nurses and physicians had lost control of this situation. When asked "How was that for you?" She shared the following:

Hard on us, because we were not able to care for him the way pediatric nurse, doc, respiratory therapist, anybody could, it was totally against your realm of practice the way you were so used to doing things. She controlled everything, she controlled our doctors, she controlled our nurses, she had full control of everything and we let her and that was very draining.

In spite of this situation, Nurse Elisa felt “bad” for this child’s mother. She thought she was a lost soul. She had no support systems in place; it was her and her son. Her son died and Nurse Elisa wonders how she is handling life.

Maintaining self.

All of the nurses spoke of the need to reflect and discuss their feelings about the unpleasant happenings in the unit. Discussing their feelings gave them a sense of purpose, a sense of closure, and an opportunity to decompress. This afforded the nurses’ the ability to safeguard themselves and continue working in the unit. They accomplished this through professional and personal support.

Colleague camaraderie and support, personal support.

The ability to share and discuss the happenings of the various situations that occur in the unit among colleagues was of great significance for the nurses. It provided the nurses an opportunity “to know that others have experienced the same thing,” it allowed for validation of their feelings. Nurse Norah spoke of a situation in which the outcome (death) of her patient should have/could have been different but do to the circumstances wasn’t. She remembers the patient yet today especially when there is another child with a similar diagnosis. Although it was an upsetting situation for her, it also became a learning experience. She recalled the following:

That was like a shell shock I guess you would say. Everything went smoothly and we all worked together as a team so it was a good learning experience. It was like this is what you’re going to be dealing with and you have to learn to handle it and compose yourself while you’re there.

It was a difficult night but the staff pulled together, they were supportive of each other's feelings and helped each other try to grasp the situation. Nurse Norah noted that she still talks with other staff about the positive things she remembers about this patient present day. She finds this a very helpful strategy to deal with difficult happenings.

Nurse Charlie said he typically keeps his emotions to himself. He spoke to his ability to keep balanced as a result of his professional relationships. Nurse Charlie has always found the PICU nursing staff to be supportive of one another especially in a time of crisis. He believes the friendships' he has formed is one of the reasons why he enjoys his job so much. Additionally, he spoke of finding solace at home. He said "It's hard, definitely hard at work but at home it's easy for me to find comfort with my wife or kids, I lean on them a lot."

Nurse Elisa recalled her thoughts about her colleagues during a shift that ended with her patient dying. She said "And you know although again it goes back to the awesome coworkers that you work with, because the second you leave that room [patient's room] they're trying to cheer you up some way." She feels very fortunate to work with such supportive colleagues.

Nurse Melissa also turns to her colleagues for validation Often times she wonders if it is just her and is she a "bad" nurse for feeling a certain way. It is reassuring for her to know other nurses are experiencing similar feelings. She also finds solace in "talking things out" with her colleagues. This strategy allows her to decompress. She also made mention that she shares her bad days with her husband. She offered the following, "I can tell my husband that I had a really bad day, kind of explain the scenario and then he will be nice to me."

Nurse Julie noted that she relies on her colleagues and family to help her through difficult times in the unit so that she can continue to work there. She tries not to take it home but often does. She chuckled as she described the following:

I think we all get a little “whacky” sense of humor working here because you have to cause if you don’t how do you deal with all of the crap? People that are here understand what it’s like so you can usually talk to your coworkers a little bit more about this. I try not to take it home but I do take it home, there’s many times I definitely do talk to my husband about a horrible case you know or something that I just went through or maybe I say to my son, you know “Hey, I just need an extra hug today because I’m really glad you’re okay” or something like that and then they know I’ve had a bad experience with a kid.

Nurse Julie tries to leave the bad situation “in check” and reminisces on the positive aspects of the child.

Crossing boundaries.

Many of the nurses made reference to crossing the line and developing a relationship of some type with numerous children and families over the years. Relationships of some type began developing with the children and their families at admission and progressed even more so if there were subsequent admissions.

Nurse Becky shared that she has “crossed the line,” and allowed herself to “become friends” with certain children and families. The most memorable relationship she developed was with a child and mother early in her career. She shared the following:

I was inexperienced and very young so I didn’t feel like I had a lot to offer them, so it was, it was just spending time with him and, and developing that relationship

over that year where we obviously clicked and connected, it was just probably my first relationship where I was attached to the patient and also to his mother, because she was there with him, she pretty much always stayed with him. One day I was summoned to his room, so I walked into his room and I said what's up XXX and he looked at me and he said I just wanted to know if you would come to my funeral and I looked at him and as a 21 year old I said, sure as long as I have directions, because I didn't know what to say to him, so and I wasn't expecting that question it was like out of the blue, you know we had formed this attachment. Nurse Becky was able to fulfill her promise to her patient and attend his funeral. He lives in her heart today.

Nurse Gregg discussed that doing the simple things for your patient can make such a big difference for the families and strengthen relationships between nursing and families. It shows the families that nursing recognizes and respects the importance of their child as a person. He shared the following:

My experience with the family and the patient regardless whether intubated or not, regardless of how responsive they are or not is, is always just talking to the patient when you're doing, as you're doing patient care explaining things. I try to make sure that they are as comfortable as I can possibly make them.

Nurse Gregg likes to engage the families in conversation as well because he learns more about the child. He believes this helps build a better rapport between him and the family.

Nurse Elisa recalled the overpowering emotions she experienced with the death of a chronically ill child that she had cared for over numerous years. She had developed a

“strong” relationship with the patient’s mother, they had become friends. She noted this was the first death that had caused her to cry in the unit.

Her [mom] saying to me, thank you so much. I never get that; I never understand how family can thank you after their child has passed away. She [mom] knew I knew what she had been through and when she looks at you and says “I wouldn’t have wanted anybody else here” and right it’s the only death I’ve ever cried on the unit on was that one.

Nurse Elisa has kept in touch with the mother.

Nurse Clare described an experience in where she thought she was doing what any nurse would do for a family whose child was dying. She changed her schedule so that she could be present for the family when their child had to undergo the second brain death criteria. She later learned of the significant impact and positive indelible mark she made on this family in the short amount of time she spent with them. She shared the following:

I knew that I wasn’t back the next day when they were going to do the second brain death criteria, so I had switched my schedule...I knew that maybe they need a familiar face. I was that familiar face that they knew... I remember mom sobbing as everything was going on...but there is a happiness to this story, we keep in contact still and they actually contacted me a couple of days ago and told me that they just had another little baby, it’s a little girl and they named her [this nurse’s name]...let me read the email that she [mom] sent “Just wanted to let you know, [baby’s name] was born on [date of birth] at [time of birth] , very healthy and happy we’re so thrilled, we like the name, but it does have special meaning to

us it reminds us of an angel who helped us through the toughest days of our lives!

This relationship will be one she remembers and cherishes always.

4.4 Summary

The goal of this hermeneutic phenomenological study was to explore the essence of the experiences of pediatric ICU nurses who provide palliative care to children with life-threatening or life-limiting illnesses and their families. The use of phenomenological reduction throughout data collection and the hermeneutic circle during data analysis generated extensive data gathered from in-depth semi-structured interviews with 12 participants. Five themes and respective sub-themes describing the participants' lived experiences of caring for these children and families were identified.

The structure of the lived experience in caring for children with life-threatening or life-limiting illnesses is a journey which includes understanding the complexity of the dying process and death of a child, appreciating the parental burden of care, recognizing and dealing with challenges to the delivery of care, maintaining oneself, and the development of special connections and crossing of boundaries as described by the participants. These themes provided insight into the intricacy of caring for these children and their families. The experiences depicted and shared by the participants provided an understanding of their journeys of providing palliative care for children with life-threatening and life-limiting illnesses and families through this difficult period.

CHAPTER FIVE

DISCUSSION

5.1 Introduction

Using a hermeneutic phenomenological approach to inquiry five major themes related to the experience of pediatric ICU nurses providing palliative care to children with life-threatening or life-limiting illnesses and their families were identified. Analysis of interviews revealed the nurses' experiences of providing palliative care was primarily focused on the dying process of children.

A discussion of the major themes in the context of the current literature is presented. Additionally limitations of the study as well as implications for nursing practice, nursing education, nursing policy, and recommendations for future research are presented.

5.2 Discussion and Interpretation of Findings

The research question guiding this study was: What is the essence of the pediatric ICU nurse's experiences in delivering palliative care to children with life-threatening or life-limiting illnesses and their families? This study's findings have not necessarily revealed the phenomenon to its fullest extent. However, it has helped uncover some of the intricacies involved for pediatric ICU nurses' when providing care to dying children.

The lived experience for this study's participants included describing the emotional impact of dying and death as inevitable and often triggering a grief response for them. They also noted satisfaction from the personal relationships developed with children and families. This enabled the study's participants to invest with meaning in

their professional role and accompany the families as they faced the possibility of death. The ability of the study participants to maintain themselves was accomplished by seeking support mainly among colleagues with whom they had shared these experiences. The findings as related to the context of the literature are now presented.

Journey to death.

The general consensus of the nurses regarding the dying process was it is unequivocally difficult for all involved. Facing the death of a child and observing the heartache that family members experienced was overwhelming for the current study's nurses. They expressed a feeling of profound sadness when this occurred. Several nurses voiced that if they did not feel sad or upset when a child died, it was time to move on. This finding was consistent with Lee and Dupree's (2007) study of 32 PICU staff. Participants of this study included nurses, physicians and psychosocial staff who cared for dying children. The staff of this study believed their sadness was a reflection of their "humanity and emotional availability" (p. 988) to families. The current study's finding of sadness was also consistent with Morgan's (2009) study in which pediatric nurses working in pediatric palliative care settings yielded recurrent themes of personal pain and sadness when children died. The feelings of sadness reported by this study's nurses were compounded when the dying child had similar characteristics to their own child.

Being available to comfort and support the families during the dying process was significant for the current study's nurses. Being open and attentive to the context of the child and family's situation allowed the current study's nurses to be receptive, appreciate what was happening, and assess how they could best help everyone at this time. This finding was comparable to Georges et al.'s (2002) grounded theory study which explored

palliative care nurses from the Netherlands perceptions' about the nature of their work in an academic setting. These authors reported that the palliative care nurses felt "being truly present and sensitive to unspoken messages" (p.790) was essential for them so they could promote the well-being of their patients.

Findings of the study at hand revealed that several nurses spoke about the closeness they had developed with the children and their families. All of the nurses acknowledged feeling sad and recognized their own grieving process with the child's death. The predominant grief reactions reported by the current study's nurses included crying, sadness, and anger. This finding parallels that of the mixed method study conducted by Papadatou, Bellali, Papazoglou, and Petraki (2002). These researchers explored and compared the grief responses and experiences of Greek physicians and nurses caring for children dying of cancer. Papadatou et al. (2002) found that caring for children dying of cancer was extremely stressful and triggered a grieving process in the staff. Grief responses included crying, sadness, anger and recurring thoughts of the dying process and the actual death of the child. Many of the current study's nurses reported they felt their grieving process was more pronounced if they had shared a close relationship with the child and family. This finding coincides with that found by Barnard et al. (2006) where Australian nurses working on a palliative care unit described not only was there a loss for the family but for them as well because of relations formed with patients and their families. Additionally, Davies et al. (1997) explored pediatric nurses' experiences with terminally ill children and reported that feelings of grief increased in proportion to the closeness of the relationship developed with the children.

Barnard et al. (2006) also reported that the close relationships formed with patients and families can be profound and at times draw nurses into vulnerable experiences.

Interestingly, one of the current study's nurses felt the need to distance herself from situations with certain families because it became too personal.

The majority of the current study's nurses confirmed they had experienced multiple losses during their careers. Many nurses noted not only had they been exposed to numerous deaths, but they were intense experiences and often were instances where deaths would occur within a short period of time. Typically health care providers are not recognized by society as grievers; however, grief reactions can occur with any loss, therefore health care providers should be recognized as grieving people when they experience the loss of a patient (Kaplan, 2000).

Caring for dying children is inevitably part of the PICU nurses' clinical practice. The nurses in the present study described trying to provide as pleasant an experience as possible for families when their child had died. For the current study's nurses that involved bathing the child as well as dressing the child in an outfit or wrapping the baby in a special blanket from home. This finding was consistent with Papadatou's (2002) study in which the majority of the nurses perceived the bathing and dressing of the child's dead body as an act of "ultimate contribution" (p.352) to the family.

Additionally, the present study's nurses voiced the importance of effective pain management especially during withdrawal of care. Many of the nurses stated they were comfortable with the administration of sedatives and analgesics to a dying child. They recognized that administering these medications could hasten the child's dying process. However, relief of pain and the prevention of air hunger was foremost in their thoughts.

While there were no studies specifically related to nursing perspectives of medication administration of the dying child, the literature is replete regarding pain management in children with life-limiting illnesses (Burns et al., 2001; Burns & Rushton, 2004; Friedrichsdorf & Kang, 2007).

A lifelong burden.

The present study's nurses recognized the important workload of parents who care for children with life-limiting and life-threatening illnesses. They value the family and what they learn from them regarding the care of their child, particularly the mothers. However, the current study nurses' described they felt the families are somewhat vulnerable as their lives rotate around this sick child and to maintain normalcy can be a challenge. This finding was consistent with that reported by Lee & Dupree (2008) where participants (nurses, physicians, and psychosocial care workers) viewed families caring for children with palliative care needs as a major undertaking. This study also reported long-term negative effects in where families could not cope with the loss of their once normal child and this often led to destruction of the family.

Challenges delivering care.

The nurses of the current study recognized the importance and need of hope for the child and family. Having hope for children with life-threatening or life-limiting illnesses is more pronounced as life is just beginning for them, not possibly ending as many of the study's nurses acknowledged it is not natural for children to die. The nurses voiced that they paralleled the family's thoughts regarding hope: being optimistic, instilling and maintaining a sense of hope and the possibility for recovery even until the time of death. The nurses did not want to take away hope even at the end; they attempted

to redefine more realistic goals of hope as death approached through comfort care, spiritual care and relief of pain for the child. These findings are similar to those in DeGraves & Aranda (2005) study in which in-depth interviews were conducted with health care professionals from three disciplines: nursing, medicine, and social work explored the challenges and complexities of caring for children with cancer who were no longer responsive to treatments. The health care professionals in this study reported they felt the need to promote an environment of hope throughout the trajectory. This was difficult for them at times because of the futility of the situation. The health care professionals believed that taking away hope could leave families feeling abandoned during this trying time (DeGraves & Aranda, 2005).

The need for clear communication between physicians, nurses, and families was voiced by the present study's nurses. They felt communication needed to be consistent and at a level of understanding for the families to facilitate informed decision making. This finding coincided with Lee & Dupree's (2008) study results regarding the importance of clear communication as crucial to avoid misunderstandings concerning the care or treatment of patients.

Many of the current study's nurses believed that when appropriate the voice of the child should be heard. The nurses stated that clear channels of communication were needed between families and the child because children are acutely aware of their goings on. This finding was comparable to that of Clark & Quin's (2007) study of professional carers' providing a pediatric palliative care service in Ireland. Physicians, clinical nurse managers, clinical nurse specialists, social workers, and palliative care teams comprised their sample. Clark & Quin (2007) noted that children, particularly adolescents, should be

given the opportunity to make a decision in their care and openly speak about their illness. Not having open discussions, especially when the child was facing death often resulted in conflict for everyone involved.

The nurses of the present study described remaining respectful of parental wishes as very trying at times. They recognized no one is typically prepared for death let alone a child's death. As parents themselves, they wouldn't give up on their child. The nurses of the present study stated they try to be mindful of parental requests and give them the needed time to accept the situation. Lee & Dupree (2008) reported a similar finding. The participants reported difficulty in accommodating the needs of families because of personal disagreement with the plan of care. The participants also voiced trying to be open-minded and considerate of everyone's viewpoint realizing it may not be their preference but it is what right for that family.

Maintaining self.

The nurses of the present study described feeling sad when a child died or something bad happened with a patient. Often times that feeling stayed with them for a while. Many nurses voiced it was important to have the ability to discuss their thoughts with someone who understood and had a similar experience. This allowed the current study nurses' validation of their feelings and the ability to make meaning of the situation. This finding corresponds with that reported by Macpherson (2008) in which the study's pediatric oncology nurses reflected through storytelling. They stated "it felt good to share with someone who 'knew' and understood the feelings" (p.155), and that they could discuss their emotions with others who had similar experiences. The current study nurses also noted the friendship and support they received from their colleagues was significant

for them. This coincides with Papadatou's et al. (2002) finding in which 75% of the nurses felt emotionally supported by their colleagues after experiencing the loss of a child.

Crossing boundaries.

The development of special relationships with the children and their families was dominant for the nurses of the current study. These relationships frequently became intense at times because the nurses were often the main support for the family, being available to listen, lean on, and share one of the most difficult times imaginable. This finding was similar to that of Barnard et al. (2006). Nurses in this study developed a close relationship with their patients and families usually after the first encounter in the palliative care environment. This closeness often continued as the patient's clinical course progressed. The nurses described their experiences as "journeying" (Barnard et al., p.9) with the patients as they went through good and bad times with the patients and families. Many of the current study's nurses described how they had crossed the lines and become friends with families over the years. This parallels findings from Docherty, Miles, & Brandon's (2009) study of pediatric nurses from various clinical settings that defines crossing professional boundaries as becoming deeply and personally involved with the child and family.

The death of a child can be harrowing for health care professionals who provide care. The cumulative impact on health care professionals that are exposed to death and routinely experience children's deaths may have a negative impact on them (Rourke, 2007). However, many of the current study's nurses voiced professional satisfaction

because of their ability to provide compassionate care to the child and family during a critical time.

Summary.

Providing palliative care to children with life-threatening or life-limiting illnesses is unequivocally complex. Pediatric ICU nurses are in a pivotal position to assist in advocating and delivering palliative care needs to the child and family. From the experiences shared by the nurses in the current study five major themes were identified: 1) Journey to death, 2) A lifelong burden, 3) Challenges delivering care, 4) Maintaining self, and 5) Crossing boundaries. These themes were relatively consistent with the literature; however, no studies specific to the study of pediatric ICU nurses were found. Interestingly, the nurses' stories were rich in description regarding death and the after death period of the child; however, this was not abundant in the literature. Moreover, the memories of children who had died that many of the nurses described were also vague in the literature. Furthermore, the literature was scant on the importance of colleague camaraderie that provided not only friendship and trust but validation of feelings during difficult situations for this study's nurses. This camaraderie also provided the current study's nurses the ability to continue working in this often taxing environment.

5.3 Limitations of the Study

This study used a phenomenological approach to discover the essence of pediatric ICU nurses' experiences in providing palliative care to children with life-threatening or life-limiting illnesses. Purposive sampling is a common sampling strategy used in qualitative inquiry. In this study, maximum variation sampling was used to attain a diverse sample of participants. However, the sample of this study was comprised

primarily of a white Caucasian population, practicing nursing in a rural healthcare setting. Perceptions of pediatric ICU nurses from other ethnic backgrounds as well as those working in an urban setting and in institutions with a pediatric advanced care team (PACT) team may describe a different experience than the participants of this study. The rich and thorough descriptions of the study's data could offer meaning in similar clinical situations.

5.4 Implications and Recommendations

Nursing practice.

Pediatric ICU nurses are at the forefront of healthcare delivery due to the significant amount of time spent at the bedside. They are in a pivotal position to recognize and respond to the palliative care needs of the child and families. However, being in this position can become an exhausting process. Consequently, it is important for institutions to recognize that a significant amount of pediatric deaths occur annually and resources should be available to assist staff with coping of these deaths. The resources could enable continuation of safe and quality care to these children and families. Therefore, the following concepts are essential for nursing leadership: fostering a positive work environment; showing respect to and for the work performed by these nurses; and providing adequate resources to promote compassion, satisfaction, and to avoid burnout.

Nursing education.

Nursing education can be enhanced by incorporating the principles of pediatric palliative care into nursing curricula. Educational efforts should include the preparation of nursing students for a professional role which includes the provision of quality nursing care to those approaching death, both in the adult and pediatric populations. Nurse

educators can use the findings of this study to sensitize undergraduate nursing students to the pediatric ICU nurses' experiences of providing palliative care. Nursing curricula may be further enhanced at the entry and graduate levels with the inclusion of concepts related to caregiver grief, compassion fatigue, compassion satisfaction and healthy work environments.

Pediatric nursing staff has not typically received formal training regarding principles of palliative care. However, national programs such as the End-of-Life Nursing Education Consortium – Pediatric Palliative Care (ELNEC-PPC) have conducted numerous training sessions to advance palliative care nursing in this setting (American Association of Colleges of Nursing [AACN], 2013). This recognized education provides pediatric nurses caring for children in various settings the tools needed to anticipate, prevent, treat, promote and advocate for the child and family during this difficult time.

Nursing policy.

Voices recognizing the need for pediatric palliative care services are slowly being heard. Traditionally, access to pediatric palliative care services has been limited due to restrictive rules of insurance eligibility, although recently there has been movement in which the six month reimbursement regulation was waived (Knapp, Madden, Wang, Kassing, Curtis, Sloyer & Shenkman, 2011). Additionally, acute crises of illness, aggressive treatment, and hospitalizations are typically covered benefits, while palliative care and hospice services may not be fully covered leaving the child and family with an inadequate health care system to meet their needs (Knapp et al., 2011). Caring for a child not expected to survive until adulthood could possibly exhaust a family's finances.

Pediatric nursing is in a unique position to organize and promote effective quality palliative care. Who more appropriate than the bedside nurse, to assess, to advocate, and to uphold the goals of pediatric palliative care?

Reform concerning pediatric palliative care begins with strategic planning and informed decision making in collaboration with local organizational leadership. The essentials of a pediatric palliative care system could consist of: continuity of interdisciplinary providers, consistent communication, individualized care and symptom management making each day the best it can be. Other considerations could include support for the caregivers caring for children at home and reimbursement for respite programs (Knapp & Madden, 2010).

Although allocation of funds is of concern as pediatric palliative care programs may operate at a loss, pediatric nursing must continue to provide convincing data, communicate and collaborate with existing health care organizations and professional coalitions to heighten public and political awareness of these programs (Knapp & Madden, 2010). Pediatric nursing should continue to advocate for these children and families to assure their needs are met across the illness trajectory.

Recommendations for nursing research.

This study has contributed to the body of nursing knowledge by providing a description of the lived experience of pediatric ICU nurses providing palliative care to children with life-threatening and life-limiting illnesses and their families, a very specialized but significant area of nursing. A recommendation to replicate this study in an urban setting institution with and without a palliative care support team may be helpful to validate or further expand this study's findings. This study could be replicated using a

different selection of participants, such as pediatric nurses working in cardiac intensive care units, intermediate care/step down units, neonatal intensive care units, bone marrow transplant units or in noncritical care specialties. This could be significant in determining commonalities among the various specialties that provide palliative care and thus enabling collaboration in the development of interventions to further support and meet the palliative care needs of these patients. Consideration of contextual factors of the setting that may influence the provision of palliative care to children could be explored.

Additional research is needed to focus on the development of strategies to further support pediatric ICU nurses' personal grieving, coping abilities, and decrease perceived work related stress as the majority of children's deaths occur in the pediatric ICU (Levetown et al., 2010). Studies are needed to determine if moral distress exists in the pediatric ICU as well as exploring what situations and personal characteristics may influence the development of moral distress, does it affect job satisfaction and what interventions are available for managing moral distress. Are they effective for this specialized area of nursing? Exploring and gaining an understanding of the family's perspective and priorities during the dying process could provide valuable information and possibly lead to an improved interdisciplinary approach to end of life care in the pediatric ICU.

5.5 Summary

The death of a child is devastating. Providing pediatric palliative care can be demanding as well as rewarding. The purpose of this study was to explore the experiences of pediatric ICU nurses who provide palliative care to children with life-threatening or life-limiting illnesses and their families and to obtain an increased

understanding of the meaning and interpretation of their experience. Through the sharing of stories, each different but yet similar, the essence of these experiences offered central context of caring for children and families with these life-threatening or life-limiting illnesses. Through in-depth interviews and probes the essence of the importance of the child and family, the giving of oneself for someone in need, the personal connection established and preservation of oneself and each other were captured and illuminated.

Through further research, policy change, enhanced nursing education, meaningful dialogue and collective collaboration with various organizational leaderships, improvements in the provision of pediatric palliative care can continue. The ultimate intent should be to increase quality of care for the child with a life-threatening or life-limiting illness and their family.

References

- Ahern, K.J. (1999). Ten tips for reflexive bracketing. *Qualitative Health Research*, 9,407.
- Ajjawi, R., & Higgs, J. (2007). Using hermeneutic phenomenology to investigate how experienced practitioners learn to communicate clinical reasoning. *The Qualitative Report*, 12(4), 612.
- Alspach, G. (2007). Retaining experienced critical care nurses: What matters most...to you? *Critical Care Nurse*, 27(2), 8.
- American Academy of Pediatrics, Committee on Bioethics and Committee on Hospital Care. (2000). Palliative care for children. *Pediatrics*, 106(2), 351.
- American Academy of Pediatrics, Committee on Bioethics. (1995). Informed consent, parental permission, and assent in pediatric practice. *Pediatrics*, 95, 314.
- American Association of Colleges of Nursing.*
<http://www.aacn.nche.edu/elnc/about/fact-sheet>
- Association for Children's Palliative Care.* [http://www.act.org.uk/what is children's palliative care](http://www.act.org.uk/what-is-childrens-palliative-care)
- Barnard, A., Hollingum, C., & Hartfiel, B. (2006). Going on a journey: Understanding palliative care nursing. *International Journal of Palliative Nursing*, 12(1), 6.

- Bontekoe, R. (1996). *Dimensions of the hermeneutic circle*. Atlantic Highlands, NJ: Humanities Press International.
- Bowden, V. R. (2005). Palliative care issue. *Journal of Pediatric Nursing*, 20(5), 309.
- Bratt, M., Broome, M., Kelber, S., & Lostoco, L. (2000). Influence of stress and nursing leadership on job satisfaction of pediatric intensive care unit nurses. *American Journal of Critical Care*, 9(5), 307.
- Braun, M., Gordon, D., & Uziely, B. (2010). Associations between oncology nurses' attitudes toward death and caring for dying patients. *Oncology Nursing Forum*, 37(1), E43.
- Burns, J.P., Mitchell, C., Griffith, J.L., & Truog, R.D. (2001). End-of-Life care in the pediatric intensive care unit: Attitudes and practices of pediatric critical care physicians and nurses. *Critical Care Medicine*, 29(3), 658.
- Burns, J.P., & Rushton, C.H. (2004). End-of-Life care in the pediatric intensive care unit: Research review and recommendations. *Critical Care Clinics*, 20, 467.
- Byrne, M. M. (2001). Evaluating the findings of qualitative research. *AORN*, 73(3), 703.
- Carter, B.S., Howenstein, M., Gilmer, M.J., Throop, P., France, D., & Whitlock, J. (2004). Circumstances surrounding the deaths of hospitalized children: Opportunities for pediatric palliative care. *Pediatrics*, 114, e361.

Children's project on Palliative/Hospice services. National hospice and palliative care organization. Retrieved from <http://www.nhpco.org>

Clarke, J., & Quin, S. (2007). Professional carers' experiences of providing a pediatric palliative care service in Ireland. *Qualitative Health Research, 17*, 1219.

Cohen, M. Z. (1987). A historical overview of the phenomenological movement. *Image 19*(1), 31.

Cohen, M. Z., Kahn, D. L., & Steeves, R. H. (2000). *Hermeneutic phenomenological research: A practical guide for nurse researchers*. Thousand Oaks, CA: Sage.

Coyle, N. (2010). Introduction to palliative care nursing. In B. Ferrell & N. Coyle (Eds.), *Oxford textbook of palliative nursing* (pp.3 - 12). New York, NY: Oxford University Press.

Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (3rd ed.). Los Angeles: Sage.

Davies, B., Cook, K., O'Loane, M., Clarke, D., MacKenzie, B., Stutzer, C., Connaughty, S., McCormick, J. (1996). Caring for dying children: Nurses' experience. *Pediatric Nursing, 22*, 300.

Davies, B., Sehring, S. A., Partridge, C., Cooper, B., Hughes, A., Philp, J. C., Kramer, R. F. (2008). Barriers to palliative care for children: Perceptions of pediatric health care providers. *Pediatrics, 121*(2), 282.

- DeGraves, S., & Aranda, S. (2005). When a child cannot be cured - reflections of health professionals. *European Journal of Cancer Care, 14*, 132.
- Docherty, S.L., Miles, M.S. & Brandon, D. (2007). Searching for "The Dying Point:" Providers' experience with palliative care in pediatric acute care. *Pediatric Nursing, 33*(4), 335.
- Drake, R., Frost, J., & Collins, J. J. (2003). The symptoms of dying children. *Journal of Pain and Symptom Management, 26*(1), 594.
- Ernst, M.E., Franco, M., Messmer, P. R., & Gonzalez, J. L. (2004). Nurses' job satisfaction, stress, and recognition in a pediatric setting. *Pediatric Nursing, 30*(3), 219.
- Espinosa, L., Young, A., & Walsh, T. (2008). Barriers to intensive care unit nurses providing terminal care. *Critical Care Nursing Quarterly, 31*(1), 83.
- Ferrell, B. & Coyle, N. (2002). An overview of palliative nursing care. *American Journal of Nursing, 102*(5), 26.
- Ferrell, B. (2006). Understanding the moral distress of nurses witnessing medically futile treatment. *Oncology Nursing Forum, 33*(5), 922.
- Field, M. J., & Behrman, R. E. (2003). *When children die: Improving palliative and end-of-life care for children and their families*. Washington, DC: National Academies Press

- Foglia, D. C., Grassley, J. S., & Zeigler, V. L. (2010). Factors that influence pediatric intensive care unit nurses to leave their jobs. *Critical Care Nursing Quarterly*, 33(4), 302.
- Foster, T. L., LaFond, D. A., Reggio, C., & Hinds, P. S. (2010). Pediatric palliative care in childhood cancer nursing: From diagnosis to cure of end of life. *Seminars in Oncology Nursing*, 26(4), 205.
- Friedrichsdorf, S., & Kang, T. (2007). The management of pain in children with life-limiting illnesses. *Pediatric Clinics of North America*, 54, 645.
- Frommelt, K.H. (1991). The effects of death education on nurses' attitudes toward caring for terminally ill persons and their families. *American Journal of Hospice and Palliative Medicine*, 8(5), 37.
- Frommelt, K. H. (2003). Attitudes toward care of the terminally ill: An educational intervention. *American Journal of Hospice and Palliative Medicine*, 20, 13.
- Gelven, M. (1989). *A commentary on Heidegger's being and time*. Northern Illinois University Press: DeKalb, IL.
- Georges, J. J., Gryphonck, M., & Deirckx De Casterle, B. (2002). Being a palliative care nurse in an academic hospital: A qualitative study about nurses' perceptions of palliative care nursing. *Journal of Clinical Nursing*, 11, 785.
- Gettner, A. L. (2010). Difficult questions for pediatric palliative care providers. *Journal of Palliative Medicine*, 13(3), 239.

- Hall, M.D. (1996). Letting go. *Nursing*, 26, 54.
- Hayslip, B. (1986). The measurement of communication apprehension regarding the terminally ill. *Omega*, 17(3), 251.
- Heidegger, M. (1962). *Being and time*. Harper & Row Publishers: Toronto.
- Himmelstein, B. P., Hilden, J. M., Boldt, A. M., & Weissman, D. (2004). Pediatric palliative care. *The New England Journal of Medicine*, 350(17), 1752.
- Hockenberry, M. J., & Wilson, D. (2010). *Wong's nursing care of infants and children* (9th ed.). St. Louis: Elsevier.
- Jones, B. L., Sampson, M., Greathouse, J., Legett, S., Higgerson, R. A., & Chrisitie, L. A. (2007). Comfort and confidence levels of health care professionals providing palliative care in the intensive care unit. *Journal of Social Work in End-of-Life & Palliative Care*, 3(3), 39.
- Kang, T., Hoehn, S., Licht, D. J., Mayer, O. H., Santucci, G., Carroll, J. M., . . . Feudtner, C. (2005). Pediatric palliative, end-of-life, and bereavement care. *Pediatric Clinics of North America*, 52, 1029.
- Kaplan, L.J. (2000). Toward a model of caregiver grief: Nurses' experiences of treating dying children. *Omega*, 41(3), 187.
- Kersten, F. (1983). *Edmund Husserl ideas pertaining to a pure phenomenology and to a phenomenological philosophy*. Boston: Martinus Nijhoff Publishers.

- Knapp, C.A. (2009). Research in pediatric palliative care: Closing the gap between what is and what is not known. *American Journal of Hospice and Palliative Medicine*, 26(5), 392.
- Knapp, C. A., & Contro, N. A. (2009). Family support services in pediatric palliative care. *American Journal of Hospice and Palliative Medicine*, 26(6), 476.
- Knapp, C.A., & Madden, V. (2010). Conducting outcomes research in pediatric palliative care. *American Journal of Hospice and Palliative Care*, 27, 277.
- Knapp, C.A., Madden, V., Wang, H., Kassing, K., Curtis, C., Sloyer, P., & Shenkman, E.A. (2011). *Pediatric Nursing*, 37(3), 121.
- Koch, T. (1994). Establishing rigour in qualitative research: The decision trail. *Journal of Advanced Nursing*, 19, 976.
- Koch, T. (1995). Interpretive approaches in nursing research: The influence of Husserl and Heidegger. *Journal of Advanced Nursing*, 21, 827.
- Kotzer, A.M., Koepping, D.M., & LeDuc, K. (2006). Perceived nursing work environment of acute care pediatric nurses. *Pediatric Nursing*, 32(4), 327.
- Lambert, V. A., & Lambert C.E. (2008). Nurses' workplace stressors and coping strategies. *Indian Journal of Palliative Care*, 14(1), 38.

- Lange, M., Thom, B., & Kline, N. E. (2008). Assessing nurses' attitudes toward death and caring for dying patients in a comprehensive cancer center. *Oncology Nursing Forum*, 35(6), 955.
- Laverty, S. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of Qualitative Methods*, 2(3), 21.
- Lee, K. J., & Dupree, C. Y. (2007). Staff experiences with end-of-life care in the pediatric intensive care unit. *Journal of Palliative Medicine*, 11(7), 986.
- Levetown, M., Hayslip, B., & Peel, J. (1999). The development of the Physicians End-of-Life Attitude scale. *Omega*, 40(2), 323.
- Levetown, M., Hellsten, M. B., & Jones, B. (2010). Pediatric care: Transitioning goals of care in the emergency department, intensive care unit, and in between. In B. Ferrell & N. Coyle (Eds.), *Oxford textbook of palliative nursing* (pp.1019 - 1048). New York, NY: Oxford University Press.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. London, UK: Sage.
- Lopez, K. A., & Willis, D. G. (2004). Descriptive versus interpretive phenomenology: Their contribution to nursing knowledge. *Qualitative Health Research*, 14, 726.
- Macpherson, C.F. (2008). Peer-supported storytelling for grieving pediatric oncology nurses. *Journal of Pediatric Oncology Nursing*, 25(3), 148.

- Malloy, P., Ferrell, B., & Virani, R. (2006). Palliative care education for pediatric nurses. *Pediatric Nursing, 32*(6), 555.
- Maunder, E.Z. (2008). Emotion management in children's palliative care nursing. *Indian Journal of Palliative Care, 14*(1), 45.
- McCloskey, S., & Taggart, L. (2010). How much compassion have I left? An exploration of occupational stress among children's palliative care nurses. *International Journal of Palliative Nursing, 16*(5), 233.
- McSherry, M., Kehoe, K., Carroll, J. M., Kang, T. I., & Rourke, M. T. (2007). Psychosocial and spiritual needs of c children living with life-limiting illnesses. *Pediatric Clinics of North America, 54*, 608.
- Meyer, E. C., Burns, J. P., Griffith, J. L., & Truog, R. D. (2002). Parental perspectives on end-of-life care in the pediatric intensive care unit. *Critical Care Medicine, 30*(1), 226.
- Morgan, D. (2009). Caring for dying children: Assessing the needs of the pediatric palliative care nurse. *Pediatric Nursing, 35*(2), 86.
- Morris, D. B. (1998). The cloak and shield: A thumbnail history of palliation. *Illness, Crisis, & Loss, 6*(3), 229.
- Moustakas, C. (1994). *Phenomenological research methods*. London, UK: Sage.

National consensus project for quality palliative care. Retrieved from

<http://www.nationalconsensusproject.org/>

National hospice and palliative care organization. Retrieved from <http://www.nhpc.org>

National network for pediatric palliative care. Retrieved from

<http://www.network4pedspallcare.org/faqs>

Nelson, J. E., Cortez, T. B., Curtis, J. R., Lustbader, D. R., Mosenthal, A. C., Mulkerin,

C., . . . Puntillo, K. A. (2011). Integrating palliative care in the ICU. *Journal of Hospice and Palliative Nursing, 13*(2), 89.

Olson, M.S., Hinds, P.S., Euell, K., Quargnenti, A., Milligan, M., Foppiano, P., &

Powell, B. (1998). Peaks and nadir experiences and their consequences described by pediatric oncology nurses. *Journal of Pediatric Oncology Nursing, 15*, 13.

Palliate. In *The Free dictionary* (4th ed.). Retrieved from

<http://www.thefreedictionary.com/dictionary/palliate>

Papadatou, D., Bellali, T., Papazoglou, I., & Petraki, D. (2002). Greek nurse and

physician grief as a result of caring for children dying of cancer. *Pediatric Nursing, 28*(4), 345.

Patton, M. Q. (2002). *Qualitative research & evaluation methods* (3rd ed.). Thousand

Oaks, CA: Sage.

- Pavlish, C., & Ceronsky, L. (2007). Oncology nurses' perceptions about palliative care. *Oncology Nursing Forum*, 34(4), 793.
- Philips, J., & Cohen, M. (2011). The meaning of breast cancer risk for African American women. *Image*, 43(3), 239.
- Polifroni, E.C. & Welch, M. (1999). *Perspectives on philosophy of science in nursing: An historical and contemporary anthology*. Philadelphia: Lippincott Williams & Wilkins.
- Rashotte, J., Fothergill-Bourbonnais, F., & Chamberlain, M. (1997). Pediatric intensive care nurses and their grief experiences: A phenomenological study. *Heart and Lung*, 26, 372.
- Richards, L., & Morse, J. M. (2007). *Read me first for user's guide to qualitative methods* (2nd ed.). Thousand Oaks: Sage.
- Rooda, L. A., Clements, R., & Jordan, M. L. (1999). Nurses' attitudes toward death and caring for dying patients. *Oncology Nursing Forum*, 26(10), 1683.
- Rourke, M.T., (2007). Compassion fatigue in pediatric palliative care providers. *Pediatric Clinics of North America*.54, 631.
- Sadala, M.L., & de Camargo Ferreira Adorno, R. (2002). Phenomenology as a method to investigate the lived experience: A perspective from Husserl and Merleau Ponty's thoughts. *Journal of Advanced Nursing*, 37(3), 282.

- Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science*, 8(3), 27.
- Showalter, S.E. (1997). Now I lay me down to sleep...remembering Walter: A child preparing to die. *American Journal of Hospice and Palliative Medicine*, 14, 293.
- Spiegelberg, H. (1984). *The phenomenological movement: A historical introduction* (3rd ed.). Boston: Martin Nijhoff.
- Streubert, H. J., & Carpenter, D. R. (2011). *Qualitative research in nursing* (5th ed.). Philadelphia: Lippincott, Williams & Wilkins.
- Sumner, L. H. (2010). In Ferrell B., Coyle N. (Eds.), *Oxford textbook of palliative nursing* (3rd ed.). New York, NY: Oxford University Press.
- Thompson, L. A., Knapp, C. A., Madden, V. L., & Shenkman, E. A. (2009). *Pediatrics*, 123(5), e777.
- Van Manen, M. (1990). *Researching lived experience*. Ontario, Canada: Althouse Press.
- Waas, H. (2004). A perspective on the current state of death education. *Death Studies*, 28, 289.
- Walters, A. J. (1995). The phenomenological movement: Implications for nursing research. *Journal of Advanced Nursing*, 22, 791.

- Weigel, C., Parker, G., Fanning, L., Reyna, K., & Brewer-Gasbarra, D. (2007).
Apprehension among hospital nurses providing end-of-life care. *Journal of Hospice
and Palliative Nursing, 9*(2), 86.
- Wolfe, J., Hinds, P. S., & Sourkes, B. (2011). *Textbook of interdisciplinary pediatric
palliative care*. Philadelphia: Elsevier Saunders.
- Wong, P., Reker, G., & Gesser, G. (1994). Death attitude profile-revised: A
multidimensional measure of attitudes toward death. In R.A Neimeyer. (Ed.), *Death
anxiety handbook* (pp.121 - 148). Washington, D.C.: Taylor & Francis LTD.
- Wright, K. (2002). Caring for the terminally ill: The district nurse's perspective. *British
Journal of Nursing, 11*, 1180.
- Yang, M., & Mcilpatrick, S. (2001). Intensive care nurses' experiences of caring for dying
patients: A phenomenological study. *International Journal of Palliative Nursing,*
7(9), 435.
- Yegdich, T. (2000). In the name of Husserl: Nursing in pursuit of the things-in-
themselves. *Nursing Inquiry, 7*, 29.

Appendix A

Demographic Questionnaire

1. What is your age in years? _____

2. How many years have you been a practicing nurse?
 - a. 0 – 5 years
 - b. 6 – 10 years
 - c. 11 – 20 years
 - d. > 20 years

3. How many years have you practiced in the pediatric ICU?
 - a. 0 – 5 years
 - b. 6 – 10 years
 - c. 11 – 20 years
 - d. > 20 years

4. What is your gender?
 - a. Male
 - b. Female

5. What is your ethnicity?
 - a. Hispanic or Latino
 - b. Not Hispanic or Latino

6. What is your race?
 - a. White – including Latino
 - b. Asian
 - c. Native Hawaiian or Other Pacific Islander
 - d. Black or African American
 - e. American Indian or Alaska Native
 - f. Other

7. What is your highest nursing degree held?

- a. Associate
- b. Diploma
- c. Bachelor's
- d. Master's
- e. DNP
- f. PhD

8. Have you had any formal education on death and dying?

- a. No, formal education on death and dying
- b. Yes, formal education on death and dying

9. Have you had a personal previous experience with loss?

- a. No, experience
- b. Yes, experience, how may? _____

Thank you for your time in completing this questionnaire



DUQUESNE UNIVERSITY

600 FORBES AVENUE ♦ PITTSBURGH, PA 15282

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

- TITLE:** Living with dying in the pediatric ICU: A nursing perspective
- INVESTIGATOR:** Debbie Stayer MSN, RN-BC,CCRN, PhD candidate
Duquesne University School of Nursing
7 Cotswold Street
Danville PA 17821
570-854-9740
- ADVISOR:** Dr. Joan Such Lockhart PhD, RN, CORLN,
AOCN®, CNE, FAAN
Professor and Associate Dean Academic Affairs
Duquesne University School of Nursing
600 Forbes Avenue
Pittsburgh PA 15282
412-396-6540
- SOURCE OF SUPPORT:** This study is being performed as partial fulfillment of the requirements for the doctoral degree in nursing at Duquesne University.
- PURPOSE:** You are being asked to participate in a research project that seeks to explore the perspectives of pediatric ICU nurses who provide palliative care. In addition, you will be asked to allow me to interview you. The interviews will be taped and transcribed. The interview is expected to last 1 -1.5 hours at a place of your convenience. Additionally you will be asked to complete a demographic information questionnaire. You may be asked to participate in a follow-up interview to review the accuracy of the interpretation of your interview by the researcher and add additional information if you should

choose; this should last no longer than 15 - 30 minutes.

These are the only requests that will be made of you.

RISKS AND BENEFITS:

There are no greater risks to participate in this study than those risks encountered in everyday life. It is hoped that information from this study will provide pediatric ICU nurses fundamental information regarding palliative care and to increase their ability to understand, identify, provide, and subsequently meet and enhance the needs of those children living with a life-threatening or life-limiting illness and their families as well.

COMPENSATION:

Participants who complete the demographic information sheet and participate in the interview process and follow-up meeting will receive a \$20.00 gift card to a local eatery at the completion of the follow-up meeting. Participation in the project will require no monetary cost to you.

CONFIDENTIALITY:

No personal identification will appear with data analysis. Your responses to questions asked during the interview may appear as de-identified quotes, however, anything that could identify you or anyone you may have referred to will have been removed. Additionally the de-identified quotes may be shared with my dissertation chair and committee members. The findings of the study may be published in a nursing journal or presented at a professional meeting. All identifying material will have been removed. A confidentiality agreement will be signed by the person transcribing the interviews. The transcriptionist will not have any access to names of participants. All written materials, taped materials and consent forms will be stored in a locked file in the researcher's home for 5 years and then destroyed.

RIGHT TO WITHDRAW:

You are under no obligation to participate in this study. You are free to withdraw your consent to participate at any time. Participation or lack of participation will in no way affect your employment either in a positive or negative manner.

SUMMARY OF RESULTS:

A summary of the results of this research will be supplied to you, at no cost, upon request.

VOLUNTARY CONSENT:

I have read the above statements and understand what is being requested of me. I also understand that my participation is voluntary and that I am free to withdraw my consent at any time, for any reason. On these terms, I certify that I am willing to participate in this research project.

I understand that should I have any further questions about my participation in this study, I may call Dr. Joan Such Lockhart, advisor of this study at 412- 396-6540, Ms. Debbie Stayer, investigator of this study at 570-854-9740 and Dr. Joseph Kush, Chair of the Duquesne University Institutional Review Board 412-396-1151.

Participant's Signature

Date

Researcher's Signature

Date

Appendix C

M.C. 30-69
100 North Academy Avenue
Danville, PA 17822
570 271 8663Tel
570 271 6701FAX

Approval Notice Initial Review (Response from PI) - Expedited Review

October 16, 2012

Debra L. Stayer, PhD(c), MSN, RN-BC, CCRN
Nursing
100 N. Academy Ave
PICU, M.C. 27-20
Danville, PA 17822
Phone: (570) 214-9200

RE: Research Protocol # **2012-0338**
“Living with Dying in the Pediatric ICU: A Nursing Perspective”

Dear Debra L. Stayer, PhD(c), MSN, RN-BC, CCRN:

Members of Institutional Review Board (IRB) reviewed and approved your research protocol under expedited review procedures [45 CFR 46.110(b) (1) and/or 21 CFR 56.110(b) (1)] on October 16, 2012. You may now begin your research.

Your research was found to have met the following specific category:

7 Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.
(NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects 45 CFR 46.101(b) (2) and (b) (3). This listing refers only to research that is not exempt.)

Please note the following information about your approved research protocol:

Protocol Approval period:	October 16, 2012 - October 15, 2013
Consent/Authorization:	Research Consent/Authorization Form, v. 10/15/2012
Study Documents:	Demographic Questionnaire, v. 10/16/2012; Semi-Structured Interview Questions & Probe Questions, v. 10/16/2012; Confidentiality Agreement for Transcription Services, v. 10/16/2012
Recruiting Materials:	Recruitment Flyer, v. 10/16/2012
Research Protocol:	Dated: 10/3/2012
Sponsor:	Society of Pediatric Nurses and Sigma Theta Tau International
Approved Subject Enrollment #:	20
Performance Sites:	Geisinger Health System

Please remember to:

→ Use **only the IRB-approved consent document(s) and/or HIPAA Authorization form(s) enclosed with this letter when enrolling new subjects.**

→ Use your **research protocol number (2012-0338)** on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements of the, "**Investigator Responsibilities, Protection of Human Research Subjects**"

Please note that the Geisinger IRB has the right to ask further questions, seek additional information, or monitor the conduct of your research and the consent process.

If you have any questions or need further help, please contact the Human Research Protection Program (HRPP) staff at 570-271-8663. Please send any correspondence about this protocol to the Human Research Protection Program (HRPP) at 30-69.

Sincerely,

John "Jove" Graham, PhD
Member,
Institutional Review Board

Enclosures: (1) Investigator Responsibilities, Protection of Human Research Subjects
(2) Research Consent/Authorization Form, v. 10/15/2012
(3) Demographic Questionnaire, v. 10/16/2012
(4) Semi-Structured Interview Questions & Probe Questions, v.
10/16/2012
(5) Confidentiality Agreement for Transcription Services, v. 10/16/2012
(6) Protocol, v. 10/3/2012
(7) Recruitment Flyer, v. 10/16/2012

cc: Susan M. Hallick (01-51)

Appendix D

Semi-Structured Interview Questions and Probe Questions

Interview Questions

1. What is it like to care for children diagnosed with a life-threatening or limiting illness and their families?
2. Please tell me what this experience has meant for you?

Interview Probes

1. Can you please explain that further?
2. Could you please tell me more about that?
3. How/what do you mean?
4. Go on...
5. Can you give me an example?
6. Is there anything else that we have not discussed that you would like to share with me before we conclude our interview?

Appendix E

Confidentiality Statement



DUQUESNE UNIVERSITY

600 FORBES AVENUE ♦ PITTSBURGH, PA 15282

I understand that I am being asked to participate in a research project in which I will have access to confidential information. I agree to keep all information pertaining to this research project confidential. I will not discuss or reveal any information to anyone outside of the research team. I have read and understand this Agreement and voluntarily accept the duties and obligations set forth herein.

Name: _____ Signature: _____

Title: _____

Date: _____ Witness Signature: _____

Appendix F

Staff Information Regarding Research Study

ATTENTION ~ PICU NURSES

NEEDED ~ PICU nurses (not currently on orientation) to participate in a research study.

STUDY ~ Exploring the essence of the experience of providing palliative care to children diagnosed with a life-threatening or life-limiting illness and their families.

PROCESS ~ Audiotaped interview with researcher to discuss your experience of providing palliative care to this vulnerable population.

TIMEFRAME ~ Initial interview will last approximately 1 – 1.5 hours with a follow-up meeting lasting approximately 15 – 30 minutes.

WHERE ~ Private area outside of the PICU or a place of your convenience.

INTERESTED PARTICIPANTS ~ Please contact Debbie Stayer @ 570-854-9740 or by email at dlstayer@geisinger.edu. Participants will receive a \$20.00 gift card to an eatery of their choice after the follow-up meeting as a token of appreciation for their time.